

5. SUMMARY OF CONSULTATION

5.1 PROCESS

Issues regarding areas to be covered by policy and protocols associated with the area of identification of carers of people with a mental illness together with suitable content for nationally consistent information requirements were discussed in focus groups and during telephone consultations with a wide range of stakeholders and key individuals [see 2. Methodology]. The following information emerged during this process.

5.2 CHANGES IN CARER EXPERIENCE SINCE 2007

The majority of participants from the public sector reported that they were generally unaware of any existing policies regarding identification of carers and that current practice continues to vary significantly from one location to another. Some exceptions to this were identified and followed up during the project. A description of these services can be found in the State and Territory Practice Section 4.

A number of carers and staff from private hospitals reported they have implemented one of the recommendations from the 2007 *Identifying The Carer* report related to the inclusion of a colour coded form as part of formal admission procedures that asks consumers, at an appropriate time to identify their carers/people they would like involved in their care and specifies the level of that involvement. We were unable to find any examples of public services implementing this process however service providers from the public sector who participated in consultations supported this process.

Many participants were unaware of the 2007 report and its availability on the DoHA web site. All felt that this information is only used by people specifically researching particular topics and that other mechanisms are necessary if the content of such reports is to be brought to the attention of service delivery staff in both public and private settings. The production of hard copies together with an implementation plan was suggested to accompany the placement of the report on the web site.

In general, participants acknowledged that there is evidence at the policy and legislative level of increased acknowledgement of carers rights for participation however, with a few exceptions, these policies are not being implemented.

In fact, the overwhelming experience of participants was that they felt health services continue to make little or no effort to identify or involve carers. Some stated they felt that the majority of clinicians did not seem to know how to go about this process. Organisational structures and culture were also reported to be counter productive to the processes of identification and engagement.

In addition, in situations where consumers voluntarily identified their carers or carers self identified there continues to be significant reluctance by many clinicians to include them in care processes. '*Consumer confidentiality or privacy legislation*' continues to be cited as reasons for non-engagement. It was the experience of participants that individual clinician attitudes and practices prevail in contravention of existing service policies.

Changes to Mental Health Legislation in the Northern Territory (2006) and NSW (2007) do appear to have had some impact on clinician practice.

Some changes were also reported in locations where Carer Consultants/Family Liaison Workers have been appointed. Unfortunately, it was reported to us that these appointments have been hampered by the following.

- Part-time nature of the appointments.
- Lack of training and support for the individuals appointed to these positions.
- Attitudes within units they have been appointed to; for example:
 - *You are not a clinician – how can we trust you with confidential information?*
 - *Thank goodness you are here – we wont have to deal with those difficult relatives anymore.*
- Exclusion from team meetings.
- Organisational structures that prohibit the person actually doing their job.
- Burnout leading to high turnover in people in these positions.

Use of the term 'carer' is not well understood by either consumers or the people who care for them. Alternative terms were discussed however all acknowledged the need to continue using the term 'carer' because of its common usage within government. The similarities that mental health carers share with 'general carers' is not well understood by people early in their experience of being the carer of a person with a mental illness. At the same time, the differences that apply to people who care for a person with a mental illness (e.g. the episodic nature of the tasks) continues to be poorly understood by government departments responsible for developing funding criteria to facilitate access to the supports required.

Participants also continued to express the view that asking consumers to identify their carers was frequently counter productive as, if they were to do this, it would be an admission that they were unable to care for themselves. Consumers' identifying their children as their carers was also considered to be problematic as some believed that by revealing this it may lead to the involvement of child protection agencies.

Organisational systems are not conducive to ongoing education and whilst attitudes of staff to consumer participation are very slowly changing this change has been at the expense of carer engagement. Existing staffing practice and systems do not facilitate young clinicians practicing in the manner in which they have been trained.

Substance abuse is increasingly pervasive and it was felt that this may further complicate family relationships and impact on the level to which people wish to be identified as caring for a consumer who may have the double stigma of mental illness, and substance abuse. This was particularly noted in situations where the consumer's behaviour has resulted in contact with the law. It was also mentioned

that significant numbers of young children are the 'hidden carers' of people, in particular single mothers, who have substance abuse problems. The issue of co-morbidity also impacts on access to services for consumers thus potentially increasing the burden of care for family and carers.

Participants noted that stigma and discrimination towards both consumers and carers is reducing in the general community and within government departments outside health at a greater rate than it is within mental health services.

Some participants mentioned the carer inclusive delivery of some of the FaHCSIA services supporting people with long-term mental illnesses to live in the community.

All participants were of the view that identification and engagement of carers is crucial in any recovery based approach to care. They also agreed that change in clinical practice will only occur if it is mandated by legislation, well grounded in policy and protocols, compliance is audited on a regular basis and incentives are associated with positive changes in practice.

Participants in the consultations also queried why there continues to be such reluctance within the mental health sector to identify carers when research clearly demonstrates that better outcomes are achieved for consumers, carers and mental health clinicians by informing and engaging carers early in the planning and on-going delivery of service.

They felt that this research that recognises that carers play a critical role in the process of recovery and relapse prevention is continuing to be largely ignored by both public and private specialist mental health services.

5.3 SUMMARY OF DISCUSSIONS OF CONSULTATIONS

- Carers have an important role to play in all situations where a person has an illness. However, specific identification of carers is most important in situations where their role is likely to be ongoing over a long period of time such as when they are caring for a person with a long term mental illness.
- The professional judgement of clinicians is recognised however no single clinician or carer can meet all the needs of all consumers. A partnership and recovery approach to care will improve consumer outcomes and decrease the burden on services and carers.
- The ideal process for identification is by the consumer. These discussions together with the degree of involvement should be negotiated, documented and regularly reviewed at times when the consumer is well. The experience of staff currently working in a carer inclusive manner is that if approached in this manner then the majority of consumers recognise and welcome the involvement of their support network.
- Some carers who self identify are not necessarily the best people to be involved in the ongoing care and recovery of consumers either because of their past history with the consumer or their own particular needs. However, these carers

continue to have rights and mechanisms need to be developed to ensure their needs are met.

- Some consumers will, from time to time, because of the nature of their illness refuse to identify or to involve carers. All professional interactions with them and written information provided to them needs to reinforce the importance of their support network being actively involved in their care.
- Consumer refusal to identify does not lessen the burden on carers. It may in some cases increase the burden of care.
- Consumer refusal to identify carers and Privacy Legislation is NOT a basis for preventing clinical staff across a range of settings from having a working relationship with the family/carer. Carers still have a right to give information to clinical staff to assist in assessment, treatment and ongoing care.
- Identification is not a one-off process. Service providers at all levels, on the basis of existing policies, Carer Recognition Legislation, Mental Health Legislation and National Standards for Mental Health Services have responsibilities to identify and support carers. Cultural and organisational change, policies, protocols, education and support will be necessary to encourage changes in clinical practice.
- Changes need to occur in all settings however specific opportunities for identification of carers exist in the following circumstances:

5.3.1 Primary care – General Practitioners (GPs)

- Participants identified the need for a poster that facilitates generic identification of all carers, including mental health carers. These could be placed in waiting rooms/locations where people are already congregating. Development of a form such as that developed by the Princess Trust in the UK was supported.
- It was suggested that similar messages could be used for TV and hard print ads with information for a single point of contact such as Carers Australia.
- The UK Greenwich Primary Care Trust protocols for carer identification were supported as important for discussion with the College of GPs to determine if they could be included as part of the Standards for General Practice in Australia. It was acknowledged that this would require incentives to be attached. Modification of the Better Outcomes and Better Access Programs was suggested as one option to further the process of identification.

5.3.2 Referral to specialist MH Care

- The GP referral to specialist mental health care, with the approval of the consumer, could specifically include carer identification including a request for contact.

5.3.3 Assessment/Admission

- Emergency Departments may be the first point of contact with the mental health system. While many Departments have introduced specific responses to concerns regarding the appropriateness of this environment to manage people who are distressed and agitated, participants indicated that little has been done to date to use this as an opportunity to identify carers.
- Participants reported that people referred, or being brought on an involuntary basis to an Emergency Department, are frequently accompanied by family members or friends. This exercise mostly involves long waiting periods and provides an ideal opportunity for identification of carers and initiation of a partnership approach to the care of the person with mental illness.
- It was considered that the same opportunities exist in first and subsequent presentations to private psychiatrists.
- Service providers consulted stated that the paperwork associated with the formal admission of a person with a mental illness to a public or private mental health service also provides an opportunity for identification of carers. The use of colour coded forms, as recommended in 2007, requesting permission from the consumer to identify carers via a structured set of questions was supported. They noted however that it may take some days for the consumer to be well enough to answer the questions.
- Consultation participants felt the completion and review of this form should be an ongoing process that is used as the basis of discussion between all parties. The form should highlight the benefits of involvement of a wider range of people in the care and support of the consumer and seek to clarify the level of involvement that the consumer feels comfortable with each person having. It was acknowledged that these levels may change over time.

5.3.4 Discharge Process

- All participants agreed that decisions and discussions regarding discharge of a consumer from an inpatient service should ideally focus on practical issues regarding availability of ongoing care and support, accommodation, future appointments and linkages to other services. They indicated that this discussion presents a further opportunity to remind service providers to ensure that carers have been identified and to emphasise to consumers the importance of continued support for their recovery.
- Carer participants strongly agreed that in undertaking these discussions staff need to be aware that carers may not view themselves as carers, but as partners, parents, sons, daughters etc.
- It was agreed that it is important that carers feel fully involved at all stages of care, including the decision to discharge the consumer. This is a process of handing over care and carers are critical partners in this process. Ideally, time should be allowed for carers to make choices about:

- Taking on, or continuing to fulfil, the role of carer; and
 - How much and what type of care they are prepared to provide, taking into consideration family and caring commitments, work, education and social activities.
- Participants felt that some people feel they have no choice but to continue to provide care even when their personal and physical resources have been exhausted, where they are afraid of the consumer, or where the consumer continues to refuse to acknowledge the role they play. This is an untenable situation for carers who self identify, and the National Standards for Mental Health 2010 and Carer Recognition Legislation now require services to listen to concerns and refer for support to meet the needs identified.

5.3.5 Continuing Community Contact

- Participants felt that this was the most important time for service providers to discuss with consumers the importance of ongoing support and to work with them to identify who provides support to them and to seek permission for these people to be actively involved in future care. This should be recorded in the notes and updated on a regular basis. The following processes were also noted as possible times to specifically identify carers.

5.3.6 Relapse Prevention Plans

- It was agreed that more emphasis needs to be placed on the development of Relapse Prevention Plans when the consumer is functioning at the best possible level. Ideally this would involve discussion with case managers and clinicians including private psychiatrists and would involve the identification of carers, including the level of involvement the consumer would like them to have. Participants stated that the majority of people with a long term mental illness know they need to have varying levels of support at different stages of their illness and are mostly happy to acknowledge this when they are well. Relapse Prevention Plans could ensure that both consumers and carers could have more say in what happens during acute episodes of illness.

5.3.7 Advance Directives for Treatment/Ulysses Agreements

- It was acknowledged that some states also have legislation in place that allows the development of Advance Directives. Historically these have been used primarily for specific instructions regarding treatment for physical illnesses and ageing, however, participants felt they could also be used by people with ongoing mental illnesses to identify who their carers are and the role the consumer wants them to play in any crisis situations and in their ongoing care.
- Ulysses Agreements were proposed by participants representing children as carers of people with a mental illness as a clear mechanism for identifying carers. A draft for such a document has been included in the appendix. Ensuring such agreements are maintained within all casenotes and kept up to date is particularly important when the caring role has been taken on by children.

- It was acknowledged by participants that not all States have this legislation available and even where it does exist it can be superseded by Mental Health Legislation. However, it was hoped that as Relapse Prevention Plans and Advance Directives support consumer driven care they are likely to receive more focus over time.

5.4 SUMMARY OF DISCUSSION REGARDING IDENTIFICATION

- Participants unanimously supported the need for policies and protocols to identify carers and stressed that no single process could achieve this. The following settings were identified as opportunities and “trigger points” for identification to occur.
 - Primary care – specifically GPs
 - Emergency Departments
 - Formal Admission to a service
 - Formal discharge from a service
 - Community care.
- For many consumers and their carers this is a rotational sequence that continues sometimes like a whirling dervish. Participants felt that adoption of a partnership approach to care between all parties would impact on the speed of rotation.

5.5 CONSUMER CONSENT

Participants also acknowledged that the process will be different in each setting depending on whether the consumer has given informed consent or not for identification and engagement. The following situations were described in the 2007 report. Participants in the 2010 consultations continued to agree with the groupings described. They also recognised the additional obligations that are potentially placed on clinicians charged with the responsibility for identifying and engaging with carers. It was also agreed that the processes developed by the Townsville Mental Health Service (see Policies and protocols – section 6) provided a useful tool to guide clinicians through this process. The 2007 descriptions have been updated on the basis of information collected in 2010 and re-presented for completeness. They have been incorporated into the policies and protocols.

5.5.1 The consumer voluntarily identifies carers

This continued to be seen as the ideal although it was felt that this could only be achieved under the following conditions:

- Development of standardised lists of question prompts to identify who provides support in an ongoing way to the consumer;
- A willingness to ask the questions and record the information when the consumer is well. Many consumers will need to develop a trusting relationship with service

delivery staff if they are to reveal sensitive information, particularly if their carer is a child or young person;

- A willingness to update the information regularly;
- A recognition by clinicians of the value of seeking to obtain this information;
- Staff possess the appropriate knowledge and skills to work with carers. This is particularly difficult when providing care to people whose carers may come from culturally and linguistically diverse backgrounds;
- Mandatory requirements such as legislation and standards that would require this (now in place); and
- Regular monitoring by way of accreditation surveys to examine compliance with the process of identification.

5.5.2 The consumer refuses to identify carers with whom information can be shared.

Identification of carers in order to obtain information from them to assist with assessment and diagnosis and to refer them for support, continues to be seen as separate from identification in order to share personal information.

Participants continue to feel that it is a staff responsibility to identify people involved in supporting the consumer via a sensitive set of questions and then to initiate contact to obtain information that could assist with development of plans that would lead to a positive outcome for the consumer. It was also felt that this was a role that could be facilitated by Carer Consultants.

Staff should also clarify with the carers what information they would like shared with the consumer. Carers also have a right to respect for their privacy and confidentiality.

It was acknowledged that consumers have the right to refuse to identify carers, however, all participants felt that obtaining this information is part of a process, not a one off event. It is necessary to regularly review these views with consumers. It was also considered important to inform carers that consent for involvement would be reviewed on a regular basis and the consumer may change their view as the treatment progresses.

It was interesting to note that it was the experience of service providers who participated in this project, as in the previous one, that consumers rarely refused to identify people who supported them. Identification depended rather on when and how the questions were asked and the reasons provided for asking.

Consultation participants were also clear that even if consumers continue to refuse to identify 'carers' it does not prevent mental health staff from working with families who self identify via their presentation or continued relationship with the consumer. The family/carers are still entitled to information of a general nature, support and referral to carers support organisations. Many examples were provided of the support obtained by carers from being referred to NGOs.

Some mental health legislation requires that carers be notified regarding specific events or clinicians are required to show just cause as to why they have not done so. This is difficult to do until they have been identified. Even where this exists, participants felt that only minimal changes had occurred in practice. These changes were primarily seen as a result of greater carer empowerment.

In addition, it was felt that at any stage of the treatment process carers who self identify should be entitled to provide information to staff to assist with diagnosis and treatment.

5.5.3 The consumer is unable to identify carers because of their mental state

Participants felt that many such situations could be avoided if Advanced Directives, Relapse Prevention Plans or Ulysses Agreements identifying carers and the desired roles they are to play had been negotiated and documented at an appropriate earlier stage of the consumer's illness. Where this had not occurred participants suggested staff should make a decision in the best interests of the consumer. In such situations it is essential to obtain information to assist with diagnosis and the development of a treatment plan.

It was noted that in some cases if the consumer has no history with the service and they were transported to the hospital by the police it may be difficult to actually identify who the carers are unless they accompany the person. Information may be obtained from the GP if one can be identified. This issue is of particular concern in situations where the carer is a young person and there are no mechanisms in place to identify and inform them what has happened to their parent.

Participants felt that in situations where the consumer's mental state is not stable staff should err on the side of caution regarding sharing of information until the consumer becomes well enough to hold an informed discussion regarding this matter. However, the same conditions should apply as in 5.5.2 above regarding provision of support to carers.

5.5.4 The consumer is a child and their ability to consent is in question

Mechanisms have been in place for some time within child and adolescent services to address this issue. These situations are governed by a range of legislation. Issues arise, however, when the age of consent varies or when the child lives independently despite being considered a 'minor'. This issue is currently being addressed in some jurisdictions where legislation is being considered to introduce the concept of a mature minor i.e. a person aged 14 to 17 years who is deemed to be able to accept responsibility for their own welfare and presumably "identify" their carer who may not be their legal guardian. In this situation, a child is then defined as a person under the age of 14.

Participants suggest that the same principles contained in the report relating to adults identifying carers should be applied except where legislation specifically provides otherwise.

5.6 SUMMARY OF DISCUSSIONS REGARDING NATIONALLY CONSISTENT INFORMATION FOR CARERS ON ADMISSION TO A SERVICE

Consultation participants suggested that the amount of information required depends on where carers are in their journey. The onset of mental illness in a family or friend can be a frightening event and even more so if it becomes necessary to involve police in transportation to hospital. Carers reported they were unable to take in a lot of new information at this time and what they were primarily looking for was reassurance that help was now available. Some reported a sense of relief that something had finally happened. Most wanted to be recognised and included in any decisions that were to be made. They wanted to be given some understanding about what would happen from now on and most of all they wanted a specific person to be nominated to maintain contact with them. All agreed they could only absorb information as they were ready for it. However a brochure containing more comprehensive information would be useful to refer back to. Carers reported finding themselves in a state of confusion and fear when recalling their first contact with a mental health service.

Participants suggested services should provide the following information to carers at the admission stage.

- Welcome message, we are here to help, outline of the processes to be followed, preferably including options for a follow up call from a designated person within the service to answer immediate concerns.
- Confidentiality – explanation of legislative requirements and re–assurance regarding options if the consumer is currently refusing in depth involvement
- Prompt questions they may use in seeking information from staff.
- Contact numbers for the hospital, ward
- Legislative status of the consumer – what this means
- Carers rights
- Complaints process
- Some general information about what the symptoms of mental illness might be
- Information as to where they might go to obtain additional information and assistance.

It was agreed that the information provided at this stage should be specific, and practically based.

Some participants also supported the provision of additional information that could be referred to as carers were able to absorb the information. Discussion ranged from including this all in one brochure to development of a total package comprising several brochures. It was also acknowledged that a lot of information already exists from Carers Australia however people generally need time to recognize themselves as a ‘carer’ so it may not be the first avenue accessed when looking for information.

It was also acknowledged that some excellent diagnosis specific information has been prepared by the RANZCP. It may, however, take a number of admissions before a specific diagnosis is agreed and everyone is willing to accept and come to terms with what this actually means. It was reported to us that in the first instance family and friends are more concerned about:

- Symptoms;
- Behaviour;
- How they (carers) should behave when their family member returns home;
- What can they expect from the person with the mental illness?
- Will they ever be like they were before? and
- What is the medication and does it have any side effects.

The terms of reference for this project required the development of nationally consistent information to be provided at admission. Following consultation it became apparent that the information needed to:

- Provide an introduction to the mental health service, explaining the processes that would be followed;
- Provide some general information about what the symptoms of mental illness might be;
- Outline in question and answer form some of the concerns they may have;
- Provide examples using the stories of family members and friends to assist them to feel less alone;
- Introduce the new language, eg 'consumer', 'carer'.
- Introduce the concept of carers rights and complaints processes;
- Introduce the issues associated with the consumers rights to confidentiality and what this might mean for the sharing of information; and
- Provide information on where to go for additional information and support.

The information has been developed on the basis of these suggestions.

Participants also re-iterated the importance of having a nominated person/Carer Consultant/Family Support Worker on staff, with whom they could personally interact, discuss and clarify information needs as required and generally use as a point of contact for future needs.

5.7 MECHANISMS SUGGESTED TO ENCOURAGE IDENTIFICATION

Participants continued to support the recommendations of the Network's previous *Identifying the Carer Report, 2007*. They sought information regarding the status of implementation of these recommendations. This information together with participants current suggestions has been summarised as follows:

5.7.1 Update of the Network's Identifying the Carer Report 2007 Recommendations

Recommendation: Carers Recognition legislation be developed by all States and Territories.

Current status: Legislation currently exists in WA, SA, NT, Qld but not in Victoria, NSW, Tasmania or ACT. However all States and Territories have carer participation policies. Implementation processes developed for this legislation are currently not paying particular attention to mental health carers.

National Carer Recognition Legislation has also been drafted.

Recommendation: Amend State and Territory Mental Health Legislation to mandate identification and support of carers/primary support persons.

Current status: Mental Health legislation is progressively changing around the country to provide more consistency however this is a long and arduous process and of the eight separate Acts, *the NT Act 2006* currently mandates more engagement than any other mental Health legislation in Australia.

Recommendation: Revise the *National Standards for Mental Health Services* to include a carer specific standard.

Current status: Carer specific standard now included. An implementation process for Standard 7 has yet to be developed. Mechanisms for specific measurement will also need to be built into accreditation survey processes such as ACHS EQUiP. This requires additional training for surveyors.

Recommendation: Develop nationally consistent packs of information for carers similar to those given to consumers.

Current status: This will be a product of the current project. Consultation participants continue to believe that admission protocols should require noting that carers have been identified and information packs provided. The availability of a Carer Consultant to support new carers to 'talk through' this information was seen as highly desirable.

Recommendation: **Develop carer identification and participation policies and protocols for implementation in each service to support changes in clinical practice**

Current status: This will be a product of this current project. Participants in this round of consultations have emphasised that opportunities for staff to receive 'carer sensitivity' and skills development training will be essential if any change is to be made in clinical practice regarding identification of carers.

Recommendation: **Appoint Carer Consultants/Liaison Officers to all services.**

Current status: Participants reported that the number of these positions has increased. It was noted that where these appointments have been made they have contributed significantly to:

- Staff support and training;
- Liaison between staff, consumers and carers, e.g. assistance with completion of admission protocols regarding identification of carers; advocacy for individual carers with staff/services;
- An increase in linkages to alternative options for information and support for carers such as referral to Carer Support Organisations;
- Provision of carer specific perspectives to staff meetings;
- Assistance with carer assessments; and
- Providing a specific point of contact for carers following discharge of the consumer.

The desirability of locating Carer Consultants in Emergency Departments, where this is the main point of entry to mental health services, also continued to be highlighted as being important in the process of identification of carers.

However we were informed that there has been high turnover in these positions primarily due to the reasons listed above.

Recommendation: **Introduce at point of entry a specific colour coded form to enable consumers to identify carers together with the level of involvement they wish them to have.**

Current status: This has been introduced by a number of private hospitals but, as yet, not by public hospitals. Participants in the current round of consultations continue to support this suggestion as outlined above under Assessment.

Recommendation: Recognise and expand the importance of the potential role that GPs could play in the identification and support of carers.

Current status: Participants continue to see GPs as potentially having a crucial role to play in the identification of carers as they frequently treat the whole family. It was felt that they are also well placed to keep this information up to date and to transfer the information when making referrals. The *Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Scheme* (Better Access) initiative, was seen as potentially playing a positive role in identification of carers.

Participants continue to highlight the need for all referral processes/forms to identify carers. This information should be an integral component of all referrals including:

- GP to psychiatrist;
- Psychiatrist to hospital; and
- Hospital to community service.

Recommendation: Modify data systems to make collection of 'carer' information mandatory.

Current status: Participants strongly support this recommendation however also felt that a short list of 'sample' questions would need to be developed to assist this process. Asking about 'carers' will not illicit the information required.

Participants noted that Child and Adolescent Services are required to collect information regarding parents/guardians/etc. Electronic data collection forms are frequently organised in such a way that it is not possible to move on to the next section until this section has been completed. Participants continue to support a similar process being developed for all admissions. It was also considered important that these questions be re-asked at every admission as just copying the information from the last admission would lead to situations where clinicians are left trying to contact relatives or friends who are no longer involved, or who have moved.

It was also felt that asking for Next of Kin does not cover this issue.

This proposal was considered by the MHISS following the publication of the Network's 2007 Identifying the Carer Report. States and Territories had varying reactions to this

recommendation. Some felt there were other mechanisms for collecting this information and others had different priorities for amendments to data collections. All noted that additional changes to data systems would entail significant cost implications.

Recommendation: Encourage people with long term illnesses to develop Relapse Prevention Plans and Advance Directives regarding care preferences and identification and engagement of carers.

Current status: The development of such Plans has been slow to be implemented in any systemic manner. Their development continues to be supported. An example of such a Directive has been included in the Appendices together with a draft Ulysses Agreement which was also supported by participants.

Recommendation: Develop legislation to provide for separate Carers Assessments as is currently available in the UK.

Current status: Participants continue to support this option as they recognise it would require services to identify carers.