



Services for People with Dementia in Wales

October 2003

Report No.3.

Advocacy Services for People with Dementia

Dementia Services Development Centre Wales

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EXECUTIVE SUMMARY

This report from DSDC Wales is the third of a series of ‘snap-shots’ of service provision for people with dementia in Wales, arising from a Service Mapping project funded by the National Assembly for Wales. It focuses on analysis of information relating to advocacy services for people with dementia. This is timely in view of the increasing recognition in policy guidelines of the need for such services; the experience gained by the existing, pioneering services will be invaluable in informing the development and expansion of advocacy services for people with dementia in Wales.

Advocacy services for people with dementia seek to help the person express his/her views, and to ensure the person’s voice is heard when decisions about their life are being made. This is necessary because dementia may impair the person’s ability to communicate effectively, and increase further the lack of control experienced by many service users. It is now recognised that channels of communication with people with dementia can be improved, but that this may require a considerable input of time, and a willingness to get to know the person as an individual, understanding their life history and life experiences.

Nine services offering advocacy to people with dementia in Wales were identified, and a key worker from each was interviewed. Five services were specifically for people with dementia (one of these was only for younger people with dementia), with the remainder having a broader remit. Most services were provided by the voluntary sector, and most had concerns regarding continuity of funding. In total, 45 staff were employed in these services, with 16 working in dementia specific services.

Most services offered an issue-based advocacy service, generally with relatively short-term involvement (six to eight sessions on average). One service made extensive use of volunteers, allocated to hospital wards. A few services worked with family care-givers as well as people with dementia, although most preferred to refer family members to carers' organisations. Referrals were received from a variety of sources; comments were made that interest in the services from care homes had increased recently.

In Wales, as in the rest of the UK, dementia advocacy services are in their infancy. Issues regarding service models, appropriate training and supervision arrangements need consideration and evaluation. Resources and guidelines on dementia advocacy have recently been published, based on a UK wide project (Cantley, et al., 2003). It is hoped that from this project networks of dementia advocates will be established in order to further the development of these services, both in quality and in quantity. DSDC Wales will seek to facilitate such a network for dementia advocates in Wales, linking in with the UK project.

Reference:

Cantley, C., Steven, K., Smith, M. (2003). *'Hear what I say': developing dementia advocacy services*. Dementia North, Newcastle-upon-Tyne.

Copies of the full report can be obtained, free of charge, from:

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Advocacy services for people with Dementia in Wales

1. Background.

1.1: The Dementia Services Development Centre Wales is a partnership between the University of Wales, Bangor and the Practice Development Unit (Older People's Mental Health Services), Cardiff & Vale NHS Trust, and forms part of the UK wide network of such centres. DSDC Wales has been operational since August 1999, providing information and resources for service providers and encouraging service development. The Centre also offers training and conducts research into dementia care.

1.2: Requests for information regarding services for people with dementia and their supporters are regularly received by DSDC Wales, and in November 1999 the National Assembly for Wales agreed to fund the establishment of a database to collect together as much information as possible on such services. This would serve to increase the information resource available to service providers, planners and commissioners.

1.3: The database has now been established, and enables detailed information on the whole range of services for people with dementia and their supporters to be collated. Like any database it is reliant on the information provided by service providers and this places limits on its accuracy and the comprehensiveness of its coverage. However, it is a dynamic electronically based system that will allow for responsiveness to service changes and developments. Now the framework is in place, there will be a continual endeavour to up-date the database and extend its coverage and usefulness.

1.4: The database allows an analysis of services by service type and by area of the country, and these analyses have proven useful in identifying areas of good practice as well as areas where there is a need for service development. Each analysis provides a snap-shot of services at a moment in time, which may enable changes in service provision to be tracked in years to come. Previous analyses have been undertaken on residential and nursing home care for people with dementia and provision for younger people with dementia. This report complements a report on advocacy services for

people with dementia across the UK, compiled by colleagues from our sister centre in the UK network of DSDCs, Dementia North (Cantley et al., 2003).

2. Advocacy services for people with dementia

2.1: Advocacy involves speaking and acting with, or on behalf of, a person (or a group of people) in order to enable them to express their wishes and needs. This has particular relevance to vulnerable groups such as people with dementia, where communication difficulties may compound the power imbalance of being a service user or the recipient of care.

2.2: The maintenance and promotion of independence is a key theme at a policy level. The Strategy for Older People in Wales gives prime importance to the promotion of independence for older people. In England, the National Service Framework for Older People (Department of Health, 2001) outlines the need to listen to older people and to enable them to make informed choices. One approach to promoting independence for older people, particularly for vulnerable groups such as those with mental health problems and people with dementia, is through the provision of advocacy services.

The need for advocacy services has been recognised by the Welsh Assembly Government (2002) in the context of developing a person-centred approach to assessments by providing information and access to advocacy services, with further encouragement coming from the National Minimum Standards for Care Homes (National Assembly for Wales, 2002):

Service users and their relatives and friends are assisted in contacting external agents (e.g. advocates) who will act in their interests (Standard 8 – Autonomy & Choice). Where service users lack capacity, the registered person facilitates access to advocacy services (Standard 11 – Rights).

The need for advocacy services, specifically for people with dementia, has been acknowledged in the Audit Commission's report on mental health services for older people in Wales (Losing Time, 2002) that states:

“The value of advocacy services is widely acknowledged. The Welsh Assembly Government has stated a desire for current services to be extended and made more accessible. Advocacy needs developing across the whole of Wales. Where advocacy is available for older people it is generally provided as part of the overall mental health service rather than a specific service.” (pp.16).

and goes on to recommend, inter alia, that:

“Health commissioners, local authorities and specialist mental health services should work together to: expand advocacy and make it more responsive to older people.” (pp. 17).

2.3: The Bournemouth judgements illustrated that people with cognitive impairment are particularly vulnerable to their rights being overridden, without the legal protection of the Mental Health Act, in situations where they passively ‘accept’ remaining in hospital or another care setting. Families often take on the role of advocate for the person with dementia, but it is widely recognised and acknowledged that the needs and interests of a care-giving relative may conflict with the needs and preferences of a person with dementia.

The prevalence of elder abuse serves as a reminder of the potential vulnerability of the person with dementia. The care-giver is also at risk, of being the recipient of aggression, or of being worn down by strain. There are concerns also regarding people with dementia living alone, in that they are potentially vulnerable to financial and other abuse from neighbours or ‘friends’. Concerns also arise in relation to paid care-workers, in that abuse may occur in care settings and in the context of community care. Fuelling these various concerns are the difficulties people with dementia may have in self-advocacy, in communicating clearly their needs, views, choices, preferences and, of course, complaints.

2.4: It is now increasingly recognised that people with dementia can be assisted to have a voice (Goldsmith, 1996; Allan, 2001). For example, one of the Council members of the Alzheimer’s Society has a diagnosed dementia. An international Dementia Advocacy & Support Network has also been established (DASN:

www.dasninternational.org). Some of these developments have been made possible by the earlier recognition and diagnosis of dementia, increasing the number of people known to be in the early stages of a dementia. However, various initiatives are also underway to explore ways of hearing the voice of people with more severe impairments. An important principle is that this takes a considerable input of time, and a willingness to get to know the person as an individual, understanding their life history and life experiences. It must be acknowledged that this can be a challenging task, requiring specific skills and experience, especially where impairments are severe, where there is a loss of judgement or where distress and agitation make communication even more difficult.

3. Types of advocacy

3.1: There are several types or models of advocacy (see Burton, 1997; Cantley et al., 2003).

- **Self advocacy.** Individuals represent and speak up for themselves. In the fields of mental health and learning disability this has involved collective self-advocacy, empowering groups of service users to have a voice and influence service provision.
- **Peer advocacy.** The advocate and client have a common background. For example, they may have shared experiences of service provision.
- **Citizen advocacy.** This involves volunteers who are recruited, trained and matched with an individual. Citizen advocacy has a long and respected history in a variety of fields, and was first described in relation to dementia in 'Living well into old age' (King's Fund, 1986). It involves a one-to-one relationship over an extended period between a volunteer and a client. This relationship goes beyond befriending and the volunteer represents the interests of the client. As dementia progresses, issues may arise regarding the person with dementia continuing to consent to the activities of the advocate.
- **Independent or paid advocacy.** This could include legal advocacy projects, but usually involves a paid worker (often with a professional background) supporting the person in a crisis or in relation to a relatively short-term need. Long-term advocacy work may be required in relation to the changing needs over time of the

person with dementia, but may be beyond the scope of paid advocacy schemes; these tend to focus on short-term work, in resolving a specific issue.

- **Volunteer advocacy.** Volunteers work alongside and are supported by a paid advocate; it differs from citizen advocacy in that the involvement may be short-term, and the volunteer may have a number of clients.

3.2: Advocacy can be distinguished from befriending, where a person shares their friendship with another; mediation where two parties are brought together to resolve issues; or counselling, where counsellors assist people in solving their own problems.

3.3: Traditionally family care-givers have seen themselves and been seen as advocating for people with dementia. The development of advocacy services reflects a recognition that whilst in many instances the interests of family care-givers and people with dementia coincide, this is not always the case, and there are numerous people with dementia who do not have close family who can take on this role in any case. Case study 1 illustrates how an advocacy service in Wales was able to work with a man with dementia in a situation where his wishes were in direct conflict with those of his wife:

Case study 1: Wife unable to have husband home

Mr P was admitted to hospital under a Section of the Mental Health Act in view of his disturbed behaviour at home. His wife's health was poor, and she was traumatised by his pre-admission behaviour. She decided she could not have him home again, and was supported by her children in this decision. Mr P wanted to go home and had been discharged from the section. The worker saw him a number of times on the ward, and discovered that he was upset that his wife had not visited him, and that although he was anxious to go home, he understood that his wife was unwell. At Mr P's request, the worker met with the wife, who could not face telling her husband of her decision. Meetings were held with Mr P and his son to discuss his options, and reluctantly he agreed to consider a residential placement, encouraged by the knowledge that his wife would be prepared to visit him there. The worker attended a case conference with Mr P and his family, and it was agreed she would introduce him to a potentially suitable home. He accepted the place, and the worker took his wife to see him after he moved in. After the 3 month review meeting, the worker's input ended as he had settled well.

Similarly, professionals (e.g. doctors, nurses, social workers) have sought to advocate for the interests of people with dementia individually and collectively. Again, situations clearly arise where the interests of professionals and people with dementia

may conflict, or where professionals are seeking to support both the person with dementia and his/her family. Accordingly, whilst family and professionals can be powerful advocates for people with dementia, the limitations of such advocacy must be recognised.

3.4: As Killeen (1996) points out, independent advocacy targeting the needs of different groups of people with disabilities is a recent introduction and that,

"the distinctive focus of independent advocacy is the development of relationships with regards to rights and representation". (p.5)

Luisa Bridgman, advocacy worker with Age Concern Morgannwg, provides a clear summary of the aims of independent advocacy services:

“to provide people with dementia with an independent voice in order to express their views, defend their rights or promote their interests”

4. Mapping advocacy services in Wales

4.1: The services in this report were identified by contacting regional and local branches across Wales of Age Concern, MIND, and the Alzheimer’s Society, enquiring regarding the availability of advocacy services within their area (not necessarily offered by their own organisation). We aimed to include all services specifically serving people with dementia, and as many as possible of the generic services who include people with dementia amongst their clients. Services offering advocacy only to the carers of people with dementia were not included.

4.2: Nine advocacy projects were identified that offer a service to people with dementia. Key workers from these projects were invited to take part in a semi-structured telephone interview (conducted between March and June 2003). The interview schedule was designed to elicit information regarding:

- demographic information
- service and operational details
- methods of referral
- staffing and training issues
- learning disabilities and dementia

- younger people with dementia
- models of advocacy

In addition, information was available from a more in-depth evaluation of one of the advocacy services, conducted by DSDC Wales in September 2002, from where the case-studies in this report are drawn.

4.3: Geographical coverage

Two advocacy services were located in mid Wales, two in North Wales, and the remaining five were located in South Wales. The catchment areas covered by each service were extensive. The areas covered were:

Gwent	Rhondda Cynon Taff and Merthyr
City and County of Cardiff	Cardiff and Vale
Carmarthen	Powys
Ceredigion	Denbighshire and Conwy
Wrexham Borough	

4.4: Service and operational details

4.4.1: Range of client groups served

Five advocacy services offered advocacy specifically for people with dementia, with one of these having a specific remit for younger people with dementia. The latter was located in an area covered by an advocacy service for older people. The remaining four services provided advocacy for people with dementia but also had a broader remit such as people over sixty, or people with learning disabilities or people with mental health problems.

4.4.2: Location

All the advocacy services demonstrated a flexible approach to service delivery, in terms of where the service could be provided. For example, all provided a service in the client's own home, if required. In addition, five advocacy projects provided an office-based service, one of which had an informal 'drop-in' service. Others provided a service within hospital wards for older people and one service had developed a community based outreach centre. The general aim was to offer a service, in the

words of one advocacy project worker “wherever the client wants”. Case study 2 provides an example of work carried out in a care home:

Case study 2: Making a decision about staying in a home

Mr J had lost his home through fire, and was temporarily living in a residential home. He was uncertain whether to remain in the home or buy another property with the proceeds from the sale of his land. There had been concerns regarding his ability to manage prior to the fire. The worker had numerous sessions with Mr J, going through the pros and cons of each option open to him. He eventually decided that the advantages of remaining in the home outweighed the drawbacks, and he appears to have a good quality of life there.

4.4.3: Numbers of clients using the service

The total number of people using the advocacy service over the last year and the number of these considered to be people with dementia was provided by six advocacy services, and is shown in Table 1 below. Figures were not available from the other advocacy services, either because they were very recently established or because the relevant details had not been recorded.

Advocacy Service	Total number of clients using the service	Number of people with dementia using the service
A	20	20
B	55	55
C	21	10
D	2800	180
E	300	7
F	300	300

Table 1: Total number of clients and numbers of people with dementia using advocacy services over previous year

Some caution is needed in comparing figures across services. The manner in which numbers are recorded varied from one service to the next. Some advocacy services simply record the overall number of contacts that are received. Not all the contacts resulted in the provision of an advocacy service with some clients being ‘signposted’

to other appropriate services. Some services did make a distinction between queries and cases, thus providing a more accurate picture of service use. One worker commented:

“If a person just needs information this is not regarded as a case and is recorded as a query. Cases are those that have extensive and prolonged contact with an advocacy worker”

4.4.4: Referral methods

The advocacy services in the sample stated that they took or would take referrals from a variety of sources. All took referrals from:

Self	Family
GPs	Psychiatrists
CPNs	Social Workers
Hospital staff	Care home staff

Self-referrals were noted to be quite uncommon by two dementia specific services which were able to identify sources of referrals. Two advocacy services commented that they did not take referrals from care home staff unless they were “senior staff”. Other sources of referral were from memory clinics, solicitors, friends and neighbours and from contacts from leaflets placed in GP’s surgeries.

4.4.5: Raising Awareness

Interviewees were encouraged to talk about issues involved in raising awareness about their service. Methods of raising awareness fell into two broad categories of direct and indirect approaches. Indirect approaches were based upon the production of written information such as posters and leaflets distributed to libraries and GP surgeries. In addition, some projects produced articles in newsletters, such as the Alzheimer’s Society newsletter, and one project had used local radio broadcasts.

Direct approaches included raising awareness of the advocacy service by delivering presentations to: social work teams, hospital staff, care home staff and carer support groups.

There were several barriers, identified by advocacy workers, to raising awareness of advocacy services. Lack of resources, in terms of both staff time and funding, was mentioned by all those interviewed. In addition, two advocacy projects commented that, although they were always looking to raise awareness, this was problematic as they were currently operating at full capacity and did not have the staff to meet any increase in demand. One of the advocacy projects that offered awareness raising sessions to residential and nursing homes in their area had encountered a poor response. However, it was noted that following the implementation of the new care standards this service is now receiving numerous requests from care homes, particularly for posters advertising the advocacy service. Although an increased demand for information is encouraging, posters alone are of limited value; many people with dementia are not able to respond to this method of information provision and care home staff may not make referrals where appropriate due to a lack of knowledge about advocacy.

4.4.6: Operation and funding

The majority (eight) of the advocacy services in the sample were operated by the voluntary sector. The remaining service was operated by a Community Health Council.

In most cases, funding was obtained from more than one source. A wide variety of sources were in evidence; for example, the use of flexibility monies from the Social Service budget, Comic Relief funding, Age Concern, Alzheimer's Society, and the Community Fund. Overall, advocacy services were constantly exploring funding opportunities. All the services holding fixed term grant monies referred to the problem of providing a sense of continuity, in terms of building upon and extending their service provision and also in terms of recruitment and retention of advocacy workers.

4.4.7: Staff and training

There were 45 staff identified as working for advocacy services across Wales. Seven of the advocacy projects employed paid staff ranging in number from one part-time worker to four full-time workers. Two advocacy services employed a mixture of paid

and voluntary staff. Sixteen staff were involved in dementia specific advocacy services.

Staff had undertaken specialist training in advocacy for people with dementia in two of the projects. A training package had been developed by an existing advocacy service and this included modules about advocacy, dementia and mental health problems in older people, communication skills, the Mental Health Act and welfare benefits and care provision. These modules were provided by specialists from each of the listed areas. Staff in another service had received induction training in advocacy with older people. Other advocacy projects relied on professional skills already acquired by existing staff members for example, prior experience as a social worker and counselling qualifications. All the volunteer workers were provided with in-house training delivered by the paid members of staff. In general, this training was not specifically tailored to advocacy skills but centred on acquiring knowledge of the benefit system, issues surrounding elder abuse, confidentiality and accessing information. In one case, training was reactive as well as proactive in terms of looking for training specific to certain issues that had occurred on a regular basis:

“If there are regular issues that come up, we try to get some training”.

4.4.8: Language and the provision of services to minority groups

All the projects stated that they could offer a bilingual service to clients in Welsh and English.

With regard to making specific provision for members of ethnic minority groups both formal and informal approaches were evident. Informal approaches consisted of dealing with the issue when it arises:

“We would recognise their needs and try to cater for them but there has been no call for this so far”

One advocacy worker had encountered a person with dementia who had reverted to his first language of Polish and had arranged for an interpreter to assist with the advocacy.

Two inner city projects were seeking to make formal provision for ethnic minority groups by seeking funding for an outreach program to reach Somali and Yemeni speakers.

4.4.9: Learning disability

Advocacy services were asked to provide information about the numbers of people with a learning disability and dementia who had used their service in the past year. Five projects stated that no clients meeting these criteria had used their service. One advocacy service, which primarily offers assistance to adults with learning disabilities, estimated that all its clients with a dementia also had a life long learning disability. Another project estimated that 3 out of a total of 300 clients had dementia in the context of learning disability, whilst the other two projects were unable to provide an estimate.

4.4.10: Younger People with Dementia

Six out of the nine advocacy projects stated that their service had been used by younger people with dementia (i.e. aged under 65) during the past year; however, accurate numbers were only available in three cases. One project dealt specifically with younger people with dementia, and all 55 of their clients were from this group. In another project that offered a service specifically for people with dementia, 20% of clients in the past year were aged under 65. This project was currently conducting research into the advocacy needs of younger people with dementia and will subsequently be applying for funding to provide specific services tailored to their needs. The necessity for service development for younger people with dementia was illustrated by an advocacy worker who commented:

“There is concern for these individuals and people are looking at what can be done...but it’s a matter of finance”

4.5: Services provided

4.5.1: Referrals to other services

Seven out of the nine advocacy projects provided referrals to other services. Two reported only ‘signposting’ their clients to other appropriate services, leaving the client to take the initiative. Active referrals were made to a variety of health

professionals, social service providers and voluntary agencies, as well as referrals to the legal profession.

4.5.2: Legal, Welfare and Financial advice

Generally, advocacy services referred clients to specialist legal services although advice might be given on issues such as power of attorney. Depending on the advocate's knowledge, in some cases, advice was provided on welfare benefits but, in general, the client was signposted to the appropriate service. Case study 3 illustrates how an advocacy project worker's intervention enabled a client to take up legal advice.

Case study 3: Issues regarding a will

The person with dementia was referred by a social worker, who had concerns that she was being influenced to change her will by a casual friend, in favour of the friend, and disinheriting her family. The social worker was concerned that she might be making a rash decision without thinking things through. The person with dementia agreed to see the worker, and appeared rational and clear in her thinking. She refused to discuss the will with the worker, but agreed to see her solicitor again, in the company of her CPN, when she decided to cancel the new draft will.

4.6: Models of advocacy

4.6.1: Working with carers of people with dementia

Three services focused exclusively on the people with dementia and did not offer a service to carers at all. Carers were referred on to other advocacy services. One well-established advocacy service, specifically for people with dementia, referred carers to a carers' advocate funded by the Alzheimer's Society. Whilst it was recognised that carers are 'natural' advocates (Killeen, 1996) for the person with dementia it was generally felt that offering advocacy to relatives within the same service, may on occasion lead to a conflict of interests. Case study 4 illustrates a typical advocacy case, where despite the presence of a number of family members, an independent advocacy service had an important role to play:

Case study 4: Patient's wishes in the midst of conflict

The client had a large family, who were in dispute regarding the appropriate residential placement for their mother. Her own views appeared to be influenced by whichever family member was around at the time. The worker spent time with the client alone, and was able to clarify her wishes. It emerged that she was actually quite clear about her choice, and had cogent reasons for it, but did not wish to offend any of her family. She agreed to the worker representing her views at a case conference, which she did not wish to attend herself. It was a difficult meeting, but it was agreed that the client would go to the home of her choice.

Advocacy services that did offer advocacy to carers as well as people with dementia stated that their main involvement with carers centred around providing assistance through transition periods, particularly when a relative moved into nursing or residential care. This is a particularly stressful time for carers (Seddon, Jones & Boyle, 2002) and issues regarding the choice of a home and financial matters were highlighted by advocacy workers as typical areas of concern for carers during this period. One project was able to offer assistance to carers by referring them to a carer support worker funded by monies from the Carers Special Grant. In some cases, the project appeared to be supporting the carer in advocating for the person with dementia; case study 5 is a good example of this.

Case example 5: Pursuing a complaint

Here the client was the wife of a man with dementia, who sustained an unexplained injury in a dementia care unit. The worker met with the client and clarified with her what she wanted to achieve, and wrote to the relevant manager on the client's behalf. The worker continued in contact with the client over many months, supporting her in placing her husband in a high quality home, continuing to pursue the progress of the enquiry on her behalf, and attending meetings with managers with her.

“It's been a wonderful support; M (the worker) has been there for me to ring. Alzheimer people would miss them if they weren't there. I'm relieved now the complaint is resolved, and I'm very happy with the home where he is now.”

4.6.2: Short term and long term advocacy

The model adopted by eight of the advocacy services in this sample was to offer an independent advocacy service on a short-term basis, usually linked to specific issues and entailing, on average, between six to eight sessions with the client. As the case studies illustrate, the range of issues includes financial matters, decisions about where

to live, conflict within families and issues regarding care services. The type of work involved includes establishing a relationship with the person with dementia, ascertaining his/her views and accompanying them to, or representing them at, relevant meetings, case-conferences etc. None of these advocacy services offered longer-term advocacy, although clients may be referred on to befriending services.

The other model, adopted by a hospital based advocacy scheme, used volunteers as advocates who were allocated to wards and built up a relationship with the person with dementia over several weeks. The volunteers were encouraged to take on the role of “best interest advocate” and were supported by a paid worker who conducted any necessary background research pertinent to each individual case. Robert Yockney, a volunteer advocacy worker in the Powys Mental Health Advocacy Service describes his role:

“advocacy input has become essential.... where the client has no close friends or relatives, there is difficulty in arriving at a conclusion satisfactory to the client’s expressed wishes and due consideration of medical history and, lastly, in the cases where the client is subject to the Mental Health Act. A typical example of an advocacy case: a referral of a case can come from one of the following, a hospital administrator, consultant, social worker, ward nursing staff or advocacy team co-ordinator; most clients are already on an E.M.I. ward. The advocate seeks the background of the particular new referral from the nursing staff, enquiring for specific items, then meets the new client and assesses whether the client is happy with you and whether you can help, bearing in mind that the client may not be communicative and the great importance of client’s wishes being paramount at all times. The length of time on each individual case can be anything from one visit to many months; you build up a professional friendship with the client and others close to them. The main aim is to arrive at the best conclusion for that person, through case conferences and meetings with key multi-disciplinary team members involved with a particular case whilst on an E.M.I. ward through to the possible discharge to the person’s home, nursing home or residential home. There is then a follow-up of at least two visits over a three week period to ensure, for example, the satisfactory general condition of the new placement, whether the client is settling in. Thereafter the advocacy work may or may not continue in each case, according to many specific points, e.g. one of my cases did not extend beyond the first two visits but, at the other end, I have one particular client who I have worked with now in a residential home since October 2001.”

None of the advocacy services offered citizen advocacy. Some issues emerged regarding the use of citizen advocates and volunteers within an advocacy service. Two key workers stated that volunteers or citizens may tend to befriend rather than act as advocate for the person with dementia, due to a lack of specialist training. The need for a befriending service was recognised by key workers but this was considered to be separate from the advocacy service. Referrals were made to befriending services where appropriate and in one case to dementia support workers. Luisa Bridgman describes how advocates may seek to lessen the impact of the necessity of closing the case once the particular issue is resolved:

“The time an advocate spends with a particular client, or how long a case remains open varies depending on the issue referred, it can be anything from 6 weeks to 6 months. Closing a case once the issue is resolved also presents dilemmas for the advocate. The advocate needs to ensure they do not create a sense of loss for the person with dementia when they need to close the case. Building a working relationship with staff at the home, involving the client as you visit, will help lessen any sense of loss. Again, asking staff to contribute or to discuss with the person with dementia the life story work can be a way of developing relationships which can help any sense of loss when an advocate stops visiting.”

5. Conclusions

5.1: This service mapping exercise has revealed the undoubted need for specialist independent advocacy services for people with dementia in Wales. As one mental health advocacy worker stated:

“we do not offer a service for people with dementia in our area, but we realise that this is a much needed service by the number of people with dementia that ask for our help. Resources should be made available to develop such a service.”

Although many independent advocacy services for people with dementia are at the embryonic stage of development they are already providing a service to many people with dementia and are often overextended. Lack of statutory funding for these services exacerbates the problems of meeting the need of people with dementia for advocacy, by limiting the numbers of staff employed and hindering future long term planning for advocacy services. The continual search for funding can ultimately

detract from the service provided, in absorbing staff time and creating morale-sapping uncertainty in staff. Accurate monitoring by advocacy services of the number of enquiries, number of actual cases and types of service user will help to draw an accurate picture of service use and offer pointers for development. It was encouraging to find that most advocacy services had conducted research prior to their inception in order to ascertain the level and type of need in their area. Areas of unmet need were being identified and funding applied for to meet that need, demonstrated by the project conducting research into advocacy needs of younger people with dementia. If the role of advocacy in care homes grows, with the implementation of the National Minimum Care Standards, then there will be an even greater requirement for the development of advocacy services, which are barely beginning to meet the needs of the estimated 9600 people with dementia in care homes (DSDC Wales Service Mapping Report 1, 2002).

5.2: There are a number of different service models developing – perhaps driven by local circumstances, the availability of funding and the existence of advocacy services for other client groups in the area. There is a need to evaluate the relative advantages and disadvantages of a ‘stand-alone’ dementia advocacy service, as against one that forms part of a wider service. There are clearly specific skills and expertise that are required to function effectively as an advocate for people with dementia, but there is a real risk of isolation and lack of appropriate support for lone advocates. Few projects are using volunteers, and there is scope to explore whether incorporating more voluntary workers is a feasible way of extending the available service. Issues of availability of suitable volunteers and the input needed from paid staff in recruiting, training, supervising and supporting volunteers need to be carefully considered. Most of the advocacy identified in Wales has been issue-based, with relatively few examples of longer-term involvement. An evaluation of whether models of advocacy that involve a longer-term relationship – such as citizen advocacy – would have additional benefits for people with dementia would be helpful in guiding the development of advocacy across the UK.

5.3: There is a need for specialist training in dementia care, relevant to advocacy, to be more widely available. Some progress is being made. A recent conference hosted by the Mental Health Advocacy in Pembrokeshire (MAP) focused upon advocacy for

people with dementia and recommended that training for advocates working with people with dementia should include: dementia awareness, communication skills both verbal and non-verbal, reminiscence and life story work. The need for these skills in forming a relationship with the person with dementia is illustrated by the following section from an article for the DSDC Wales Newsletter, written by Luisa Bridgman, advocacy worker with Age Concern Morgannwg:

“To our clients the advocate would initially be a stranger. Time needed to be allowed for relationships to be established. We found we needed to look for ways our visits would allow a relationship to develop and still tackle the issues referred that were causing the person with dementia concern or distress. The advocate always tries to get to know as much as they can about the client. This is very important as it can sometimes be hard for a person with dementia, in a care home, to maintain their individuality and sense of self. We found, in some cases, life story work to be a very successful way to establish a relationship.

Initially we used life story work to help communication between the advocate and their client, to help the advocate to build a picture of their client’s life and most importantly to provide the client with something tangible to say “this is me”. Our work involves recording in a book, mainly in picture format, the main events and people in a person’s life. These books are not always a complete record as often the information or pictures available inevitably have gaps. However this work has allowed an advocate to know a person and be able to relate the issues being advocated for to the person’s life. Another positive outcome is that it has enabled others involved with the client to ‘see the client as a whole person with a life time of living’.”

5.4: Supervision for paid and volunteer advocates is vital if they are to carry out their difficult role effectively. Ethical dilemmas are often encountered in this field, and pressures from families and professionals have to be, at times, resisted. Luisa Bridgman describes the importance of making clear to all concerned the role of the advocate:

“Once a referral has been made the advocate meets the person with dementia and establishes if that person would like an advocate to work with them and what support they feel they need. The advocate then continues to visit the person and establishes a relationship making sure all involved, including the initial referrer, understand the advocate only supports the person with dementia and will only represent their views. The relationship between the advocate and the client (person with dementia) is fundamental to how successful the advocacy work is. The advocate needs to be sure, if the client is unable or unwilling to attend meetings, that the advocate clearly expresses their client’s wishes.”

It can be difficult at times to be sure exactly what the client wants, and supervision provides a means of ensuring the advocate does not, unwittingly, pursue their own agenda. The development of closer links between advocacy projects in Wales would help to facilitate the development of appropriate training and supervisory arrangements and would also enable advocacy services to support and inform each other about best practice. Established inter service links would also ameliorate the sense of isolation felt by those who are working alone at present.

5.5: Dementia North, the DSDC for the North of England, has recently completed a two-year UK-wide review of advocacy for people with dementia (funded by the Department of Health), culminating in a report containing valuable guidelines and resources for those developing and operating these services (Cantley et al., 2003). Dementia North has been funded until April 2004 (again by the Department of Health) to provide information about dementia advocacy and to encourage the development of learning networks for dementia advocates. This provides an excellent opportunity to develop services and expertise in Wales also, and DSDC Wales will seek to facilitate the development of a network of dementia advocates in Wales, through its web-site and through arranging meetings for those interested, with input from our colleagues in Dementia North.

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7. Project Team

The following past and current staff have made significant inputs to the service mapping project:

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Many thanks to all those in services in Wales who have responded to our questions patiently and courteously.

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