

Welsh Speakers' Experiences of Health and Social Care Services



Cyngor Gofal Cymru
Care Council for Wales

Hyder mewn Gofal - Confidence in Care



Llywodraeth Cymru
Welsh Government

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Executive Summary

1. The research aims to contribute towards informing the Strategic Framework for the Welsh language in Health and Social Care services in Wales, by exploring the experiences, views and insights of users of health and social care services and their carers. Four priority groups are covered: children; older people; mental health service users, including those with dementia, and people with learning disabilities.

2. The research set out to receive evidence from a minimum of 40 respondents and aimed at an optimum number of 60 (that is, a minimum of ten respondents for each priority group, or an optimum of 15). To achieve this, local and national media were used to ensure broad based coverage of the research and an invitation to respondents to take part.

3. A total of 51 responses were received during the period from mid January until 31 March 2011:

children	17
older people	15
people with mental health problems	10
people with learning disabilities	9

Of mental health service users, four had been diagnosed with dementia

4. A relatively broad based response was received from several parts of Wales, as outlined in Table 2 (page 11). The pronounced cluster of respondents from Ceredigion has to be recognised and may reflect the fact that the research team was based locally rather than the existence of a distinct set of local concerns.

5. One of the limitations to be acknowledged is that recruitment methods may have favoured those respondents who felt least stigmatised by their circumstances. But, the help provided by service user organisations enabled the inclusion of more marginalised and vulnerable voices.

6. Despite inviting both positive and negative responses, the majority of those received related to weaknesses in service provision rather than to strengths and examples of good practice.

7. Essentially, respondents referred to three levels of Welsh-medium service delivery: the optimum level, where all aspects of the service are delivered in the user's preferred language; the least favourable, where services are delivered in English and little, if any, acknowledgement is given to the user's language. Users often withdraw and stop using these services, feeling that they are both inappropriate and ineffective. Between these levels lies the compromise model in which English-speaking professionals take practical steps to acknowledge the user's language. Respondents appear to value such displays of language sensitivity, or what is described by one respondent as 'professional humility.'

8. Several respondents refer to the importance of identifying language use at the outset and using this information to shape subsequent service delivery. They imply that the onus should be placed on the service provider to ask the question rather than on the service user to identify the need. This information should then accompany users as they proceed through the system and be flagged up at each new referral point.

9. Individuals in several parts of Wales refer to the impression that Welsh medium services are often the product of accident, not design. 'The good practice, when it happens, occurs organically,' says one respondent. That is, it reflects its local, bilingual workforce rather than being the product of conscious planning.

10. Respondents identify the link between language and care and refer to examples which imply that the quality of care to vulnerable users may be compromised by the failure to communicate in their first language. The evidence provided in relation to domiciliary care services and residential care facilities for older people suggests the need to pay attention to language-appropriate provision in service procurement arrangements, through third party contractual agreements.

11. Mental health service users provide evidence which conveys the importance of providing language-appropriate therapeutic and psychiatric services. For many, their use of English to access their inner, emotional world does not enable them to make the best use of the service being provided.

12. Respondents across each of the four priority groups speak of the reticence on the part of health and social care staff to use their Welsh language skills. Several respondents suggest the need for employers to acknowledge and value Welsh language skills at all levels within the workforce and to develop support systems to enable staff to further develop and strengthen their skills.

13. Respondents refer to the value of bilingual health and social care practitioners as part of the clinical / care team; more needs to be done, they say, to plan more consciously for bilingual team working in the priority areas covered by this research.

14. GP based services do not always reflect the language profile of the communities they serve. Respondents suggest that greater attention should be given to language skills at appointment; this may include making available intensive and function specific language skills training, as well as more support for health care staff at all levels to acquire a sounder awareness of language use in their work with patients.

15. Specific challenges are posed by the growing numbers of Welsh speakers in urban Wales. Whereas the evidence from parents in these areas tends to suggest that, on the whole, they may be more vociferous and assertive in challenging the gaps in service provision, for other user groups there is a sense that they suffer double jeopardy as vulnerable, sometimes marginalised service users who speak a minority language and live in communities where there are often significant numbers, albeit low percentages of Welsh speakers.

16. The importance of language-appropriate assessment is raised with particular reference to dementia and children's services – speech and language therapy; eye and hearing tests, and health visitor assessments. Other examples also highlight the vital role of language as a diagnostic tool. Issues regarding the accuracy of assessment via translation are raised by several respondents.

17. For many respondents, the use of the preferred language is powerful in terms of creating affinity and forming closer professional relationships.

18. Respondents often refer to being told that services are either not available in Welsh or that they face delays in receiving a Welsh-medium service. Evidence of delays is quoted in the main body of the report.

19. Many users and carers across each of the four priority groups say that Welsh-medium services are delivered on the basis of demand rather than need. This is unlikely to produce significant improvements in Welsh medium delivery. The low expectations of the majority of Welsh speakers as speakers of a traditionally marginalised, minority language as well as an underpinning reluctance or inability on the part of often disempowered individuals to complain about health and social care services, both militate against the ability to effectively challenge the services being delivered.

20. Respondents make several suggestions regarding the possible changes and improvements needed. These relate to workforce development, valuing bilingual service delivery on both an institutional and individual level, and building into administrative and professional systems ways of identifying language needs and making intelligent use of data. More specifically, they recommend:

- i) More vigorous efforts to recruit Welsh speakers to the health and social care sector.
- ii) The importance of gathering data on language use and preference at the point of referral and using this to guide appropriate interventions.
- iii) The need to identify the level of language skills in the workplace, using this as a baseline to provide appropriate training to enhance skills and confidence.
- iv) Continuing professional development opportunities for all health and social care staff to foster a sounder understanding of the relevance of language-appropriate service delivery.
- v) The continuing professional development of health visitors with a view to enhancing their understanding of the process of language acquisition for young, monolingual children in Wales.
- vi) The use of practical tools such as the *laith Gwaith* badge to help identify Welsh-speaking staff.

1. Context and Aims

1.1 The overall aim of the research is to contribute to the process of informing the development of a Strategic Framework for the Welsh language in Health and Social Care services in Wales, by exploring the experiences, views and insights of users of health and social care services and their carers.

1.2 In this respect, the research updates and builds upon the existing knowledge base in relation to the experiences of Welsh speakers as users of health and social care services. It follows in the tradition of other pieces of qualitative research in Wales, for example, Roberts (1994);¹ Thomas (1998);² Madoc-Jones (2004);³ Prys (2009)⁴ and the more extensive review of the health service undertaken by Misell, (2000)⁵.

1.3 As in Misell's work, this research also has as its focus four groups of service users for whom communication in one language rather than the other is a matter of necessity rather than a concession and where it appears, based on the above research, that there may be a close link between language use and the quality of the intervention or the service delivered.

1.4 The priority groups identified are:

children

older people

¹ Roberts, G., 1994, Nurse/Patient Communication within a Bilingual Health Care Setting, *British Journal of Nursing* 3(2)

² Thomas, G., 1998, *The Experiences of Welsh-speaking Women in a Bilingual Maternity Service*, Unpublished MSc dissertation, Cardiff: University of Wales

³ Madoc-Jones, I., 2004, Linguistic sensitivity, indigenous peoples and the mental health system in Wales, *International Journal of Mental Health Nursing*, 13 (216-224)

⁴ Prys, C., 2009, *Defnydd o'r Gymraeg yn y Trydydd Sector yng Nghymru*, Unpublished PhD thesis, Bangor: University of Wales

⁵ Misell, A., 2000, *Welsh in the Health Service*, Cardiff: Wales Consumer Council

mental health service users, including those with dementia, and people with learning disabilities.

1.5 The research therefore set out to investigate the experiences of Welsh speaking service users in these four areas, inviting responses from either users themselves or their carers, and confining its data collection to experiences which have occurred during the last three years.

2. Methods

2.1 The research set out to receive evidence from a minimum of 40 respondents and aimed at an optimum number of 60 (that is, a minimum of ten respondents for each priority group, or an optimum of 15). To achieve this, local and national media were used to ensure broad based coverage of the research and an invitation to respondents to take part. Editors' letters were therefore sent to 46 local weekly newspapers and a Press Release was distributed to the *Western Mail*; *Daily Post*; *Golwg*; *Y Cymro*; the S4C afternoon programme *Wedi 3*, and the BBC Radio Cymru morning chat programme, *Nia Roberts*. Letters were also sent to:

each of the 38 *papurau bro* (community newspapers)

four denominational magazines

21 *Mentrau Iaith*

12 Community Health Councils

six third sector agencies working with the priority groups identified for the research.

2.2 Information about the research was also circulated to relevant officers in the Welsh Language Board and *Merched y Wawr*. (Sample copies of publicity material: Annex 1).

2.3 Both *Wedi 3* and the *Nia Roberts* programme carried an interview, and *Merched y Wawr* used their Care Panel as a forum to share information about the research with its members.

2.4 By the last week in January and the early weeks of February 2011, media coverage brought results as respondents started making contact with the research team. Added to this, the links made with service user organisations ensured a steady trickle of interest throughout the research period, with interview

and written evidence being received through until March 31. The support of service user organisations proved particularly helpful in strengthening the number of responses from the two user groups for whom the research methods proved most problematic, namely mental health and learning disability service users.

2.5 One of the limitations which have to be acknowledged is that the recruitment methods may have favoured those respondents who felt least stigmatised by their circumstances. The number of responses on behalf of children, as seen in Table 1, suggests that many of the parents who responded felt confident and motivated to share their experience. For more vulnerable service users, the motivation required to respond and the confidence needed to articulate and disclose personal information posed difficulties potentially. However, as suggested above, the help provided by service user organisations enabled a few of the more marginalised and vulnerable voices to be expressed.

Table 1: Number of responses by service user category

Children	17
Older people	15
People with mental health problems (including dementia)	10 (of whom dementia: 4)
People with learning disabilities	9
Total respondents:	51

2.6 The optimum number of responses was therefore received for two of the priority groups, with one of the remaining two groups reaching the minimum threshold of 10, and the other falling just below this with nine respondents taking part. However, some of the children for whom evidence was received also fell into this latter group of users with learning disabilities.

2.7 In terms of geographical distribution, a relatively broad based response was received across several parts of Wales, as outlined in Table 2. The pronounced cluster of respondents from Ceredigion has to be recognised and may reflect more the fact that the research team was based locally than the existence of a distinct set of local concerns.

Table 2: Number of responses by geographical area

Anglesey	2
Cardiff	6
Carmarthenshire	4
Ceredigion	17
Conwy	3
Denbighshire	4
Gwynedd	4
Neath Port Talbot	1
Newport	1
Pembrokeshire	2
Powys	1
Rhondda Cynon Taf	2
Swansea	2
Vale of Glamorgan	1
Wrexham	1
Total	51

A detailed breakdown of responses for each of the priority groups by geographical area may be found in Annex 2.

2.8 On making contact, participants received a letter outlining the background of the research and the uses to be made of the evidence gathered. They were also

asked to complete a consent form and to identify the way in which they wished to contribute evidence. Copies are available in Annex 3.

2.9 Completed consent forms were received from 56 individuals. Of these, 51 provided evidence; five respondents who had stated a wish to submit written evidence had not yet done so at the time of preparing this report.

2.10 Before submitting evidence, respondents received a set of research questions which offered a basis for their response. However, in addition, all respondents were invited to raise any additional issues to illustrate their specific experience. Research questions are included in Annex 4.

Table 3: Number of responses by type

Pre-arranged phone interview	22
One to one interview	20
Written evidence by letter / e-mail	9
Total	51

2.11 In conclusion, the findings are based on research undertaken within a tight time frame, January – March 2011 and on a small sample of 51 respondents, many of whom were sufficiently motivated and able to respond to the recruitment methods adopted. Additional time may have made it possible to reach and include more vulnerable individuals whose voice is least likely to be heard.

2.12 Despite inviting both positive and negative responses, the majority related to weakness in service provision rather than to strengths and examples of good practice.

2.13 While focusing on the experiences of service users in the four priority groups, some evidence also relates to the language needs of carers and parents.

3. Research Findings: The Experience of Users and Carers

3.1 Introduction

In drawing together the research evidence, very little attempt is made to analyse or comment on the experiences of service users and carers. In the use made of verbal and written evidence, an attempt is made to reflect as accurately as possible the real voices and perspectives of the individuals who took part. Experiences have been drawn together thematically; some are located geographically and there are a few issues which have particular regional implications. But for the most part, many of the experiences and perspectives referred to appear to be relatively consistent across Wales.

3.2 Setting the context

3.2.1 The parent of a child in Gwynedd, with multiple learning and physical disabilities, draws on their experience as a family during the past ten years. By doing so, she summarises the range of experiences which were addressed by many respondents. Essentially, there are three kinds of language based services, she says. Firstly,

‘We receive a number of services in Welsh, for example, from our GP, our social worker and all the education based services. In all these services, X our son, can be included fully in every discussion; he can express his opinion clearly and the professional can get to know him as an individual with his own opinion and ideas. Being a child with disabilities, he has to receive a lot of help with day to day things, so anything he can do for himself, such as communicating, is a real boost for his self confidence.’

3.2.2 This is the optimum service, she says. At the other end of the continuum, she reflects on the least satisfactory kind of service.

'We receive other services where the worker speaks no Welsh at all ... with these services, X isn't able to take part in discussion, he can't express an opinion directly, and without any doubt, the worker can't get to know him as an individual, because they have to communicate through us as his parents. Whatever the professional standard of this kind of service, it can't be a good service essentially because one key factor is missing – the ability to communicate with the patient himself.

'We've come across examples of professionals behaving quite inappropriately, mostly I think because of a lack of training and awareness. We've come across lots of professionals who ignore X completely when he speaks Welsh with them. I have to ask them to respond to him and I suggest appropriate words, such as "*da iawn, X*" ... We've stopped using some services because not only are they not available in Welsh, but because staff show so little understanding. We lose confidence in their professionalism overall, and we feel a lack of respect towards them generally.'

3.2.3 Other respondents, especially parents of children with disabilities, make a similar point, saying that they withdraw and stop using English-medium services, feeling that they are inappropriate and therefore ineffective for their children.

3.2.4 The third kind of service referred to by this parent from Gwynedd is a half way point,

'We've come across some services half way between what I've mentioned already, where the professional is able to communicate to some degree with the child in Welsh. They apologise for failing to do better (therefore recognising that this is a weakness in the service) and communicate in English with the parents ... They show respect for your situation and they make you feel more at ease.'

3.2.5 Many respondents make a similar point, saying how much they appreciate the steps taken by English-speaking professionals to acknowledge their language by using a few words of greeting or introduction. According to one older person,

‘They try saying something and you try helping them and that helps the relationship.’

3.2.6 The mother of a young man with learning disabilities reflects on their GP’s use of Welsh with her son,

‘He’s ever so supportive; he tries his best to use a bit of Welsh with X. When he examines his ears, he says things like “*golau mlaen, ti isio dal hwn*” ... X has a fear of having his ears treated, but he relaxes.’

3.3 Language sensitivity and ‘professional humility’

3.3.1 One respondent puts this clearly,

‘It’s not practical to expect everyone to be able to communicate in Welsh but everyone can show respect and flexibility. Professionals need to take a step back and show a bit of professional humility ... It doesn’t have to cost money. It’s about attitude, the wish to improve.’

3.3.2 One parent refers to her experience of taking her son to Alder Hey Children’s Hospital, Liverpool on a regular basis and being surprised and pleased on her first visit to be greeted in Welsh by a receptionist who was able to refer to a list of greetings in several languages and say, ‘*Bore da, sut ydych chi?*’

3.3.3 The doctor responsible for her son’s care in Alder Hey would also acknowledge her son’s language and background by saying things such as, ‘Tell

me, X, how do I say this in Welsh?’ This helped to create rapport and form a clinical relationship between doctor and child, she says.

3.3.4 Another parent commenting on the scarcity of Welsh-medium psychiatric services suggests that

‘Oddly enough, it was in a psychiatric unit over the border in England that we had the greatest understanding about having to cope with X’s illness through the medium of our second language and that came from a family therapist who came from Switzerland and who was also communicating in her second language.’

3.3.5 Conversely, respondents describe situations in which very little sensitivity or respect were shown for language, as in this example from a carer whose mother, with dementia, was being cared for in a west Wales hospital,

‘She was instructed by more than one nurse to speak English. “*Mae hon yn gas i fi,*” my mother said to my brother about a nurse who was inserting a needle into her tummy to prevent the blood from clotting. “You should speak English so that I can understand you,” the nurse said to her. Many of the staff had no idea about the need to understand the emotional needs of a Welsh speaking patient who was confused.’

3.3.6 The theme of professional humility was picked up in the experience of another parent,

‘When X was really little, I’d left him for two minutes with a therapist who didn’t speak Welsh. X had turned round and said “one, two, three, four, five, six, seven, eight, nine, ten,” that is, every English word he knew at the time. She couldn’t understand why he’d said this to her so I had to explain. “He’s using all the English words he can to communicate with

you. He has a learning disability; you are a professional person. Is there anything you think that you can learn from what has just happened?”

3.4 Identifying language use – shifting the onus from user to provider

3.4.1 For many respondents, language often remains a hidden or unacknowledged factor in their relationship with health and social care providers. This is summed by an older person who refers to her monthly appointments at an eye clinic.

‘I go to the eye clinic once a month. Nobody has asked which language I’d prefer and it’s English which is offered.’

A mental health service user relates her experience,

‘When I phoned to talk to the person I was supposed to see, I asked if she spoke Welsh and the only answer I had was “No” - quite bluntly.’

Nobody raised the language issue again. The service user didn’t feel that it was something she could return to, although ‘... I’d have preferred to be able to speak about things in Welsh.’

3.4.2 Several respondents refer to the importance of identifying language use at the outset and using this information to shape subsequent delivery. The onus needs to be placed on the provider to ask the question rather than on the service user to identify the need. This is particularly pertinent for vulnerable service users in priority groups, many of whom may not be in a position to flag up the need themselves. Even if service providers are unable to respond appropriately at the time, data may be collected regarding unmet need and used to inform language skills and workforce development strategies.

3.4.3 According to one father,

‘If the child is monolingual, then you should be *offered* the service in Welsh without having to ask ... If an English speaking child had a Welsh medium service, there’d be plenty of fuss.’

3.4.4 The carer of a person diagnosed with dementia says,

‘I’ve made the point from the beginning, can we have services in Welsh please? Having said that, we still tend to have to raise the point again at every step in the process.’

3.4.5 A parent from north east Wales summarises, ‘It’s a pity that they don’t ask about your language choice right at the beginning.’ She implies that leaving it until you are face to face with your allocated professional is too late.

‘If you say something then, it’s as if you’re saying, I don’t want *you*. It feels too personal. The system needs to flag up the whole thing. It would be more neutral then.’

3.4.6 Other respondents also refer to the need for the system to identify individuals’ language choice at the point of referral and for that information to accompany them as they proceed through the system and be flagged up at each new referral point. This is raised by a parent from Carmarthenshire whose young child has been referred for speech and language therapy.

‘The letter came from the Health Board in English only although I’d asked for a Welsh-medium service. After receiving the letter, I phoned them to say that we needed someone who speaks Welsh only to be told that they only have one therapist who speaks Welsh in Carmarthenshire and that they have a waiting list of 10 weeks.’

3.5 Welsh medium services – accident or design?

3.5.1 Individuals in several parts of Wales refer to the impression that Welsh-medium services are often the product of accident not design. For a respondent living in south west Wales, 'It's a matter of accident ... It depends who's available at the time.'

3.5.2 In Gwynedd, respondents contrast the extent of Welsh medium services provided by the local authority social services department on the one hand and what appears to be the more ad hoc provision made available by the local health board. One mother says,

'Every social worker we've had over the years has been a Welsh speaker. That's crucial for us. As a mother I'm the one who speaks for X, and I'm more comfortable in Welsh. But all the health clinics are in English; we have difficulty understanding sometimes. When you have someone who speaks Welsh, it makes such a difference.'

3.5.3 According to one respondent, 'The good practice, when it happens, occurs organically.' He argues that it may not be a result of conscious planning but rather a reflection of the way in which health care providers in north-west Wales are able to attract a local workforce, a significant percentage of whom have bilingual skills.

3.5.4 Another parent refers to the irony of having his young daughter transferred from the children's ward in a hospital in west Wales, where no Welsh-speaking members of staff were available at the time, to the children's hospital in Cardiff.

'I went up to the ward and I could hear my wife speaking Welsh. I thought that my mother had arrived. But I realised then that the doctor spoke Welsh – oh, fantastic. There was a nurse on the ward who spoke a bit of

Welsh too. That helped X, who was three at the time and didn't speak English. She hated having the needle put in but she used to relax with the nurse who spoke a bit of Welsh. She could use Welsh to explain what she was doing.'

3.5.5 The failure to take account of the language profile of users and workers was brought home in the experience of a young mental health service user in north east Wales. She only found out after her professional relationship with her psychiatrist had come to an end that he was able to speak Welsh.

3.5.6 Another mental health service user in south Wales relates how finding out that her psychiatrist was a Welsh speaker happened purely by accident. 'Neither the psychiatrist nor anyone asked if I spoke Welsh.' It was only when she referred to her occupational background that both became aware of the language. Being able to use the Welsh language in the therapeutic context was very valuable, she says.

'It was wonderful for me. I was depressed. And I wasn't using Welsh every day. The skill had been brushed under the carpet ... But I realised, I'm still a teacher. It was amazing for me. When I was depressed, all the skills had gone. Everything was pointless. But having the opportunity to speak Welsh – wow ... It was a turning point in the process of getting better.'

3.6 Language and care go hand in hand

3.6.1 A few of the families who took part in the research refer to the way in which language and care are inextricable. One relative describes the implications for an elderly couple who were being cared for at home by a private domiciliary care agency. Carers visited their home three times a day,

‘Lots of them didn’t speak Welsh and that added to their confusion. They’d ask things like “would you like supper?” and they’d say that they’d had food when they hadn’t really.’

3.6.2 In this situation, the family felt that ‘... the care and the language went hand in hand,’ and that the quality of care was compromised by the failure to communicate with both service users in their first language, ‘... the only language that had ever been used in their home.’ This led to mealtimes being skipped, the family say, to clothes not being changed, and to an overall failure to offer adequate care.

3.6.3 A complaint was made to the local authority, a Protection of Vulnerable Adults inquiry was undertaken and a new team of carers installed who were able to speak Welsh. This, according to the respondent, had a direct impact on ‘the care relationship.’ Sharing the same language and cultural references, she says, made it easier for these carers to get to know both users - to “coax” them to eat and wash, for example.

‘Language was marginal to them in the agency but it was key for them as a couple.’

Another respondent refers to language as an essential consideration in caring for a relative with dementia,

‘I’ve had to insist on having someone who speaks Welsh. The morning is so important. When you’re woken up in an unfamiliar language, it isn’t a good start to the day ... If X is woken up in her own language, she’s more perky ... The person who comes in the morning is learning Welsh, she speaks Welsh with X and English with me.’ And that works well, he says.

3.6.4 The evidence of both respondents suggests the centrality of language in caring for vulnerable individuals and therefore the importance of paying attention to language-appropriate provision in service procurement arrangements, through third party contractual agreements, for example.

3.6.5 For the mother of a young man with multiple disabilities, language and care also go firmly hand in hand. She describes an incident which arose when his carer at the time, a Welsh learner, failed to understand him. This led to a spiral of misunderstanding and anxiety, as she relates

‘X asked for *Cerddwn Ymlaen* (the Dafydd Iwan song). The carer didn’t understand and he switched the computer on. X lost his cool and everything went from bad to worse. It was a misunderstanding but X got angry and his behaviour became more challenging. It was all down to communication. But I was worried about his blood pressure as he was so worked up.’

Since then, there have been changes to his support programme and

‘By now, everybody who cares for him is a Welsh speaker; everybody also communicates in the same way using PECS (Picture Exchange Communication System) and we don’t have that big temper anymore. We’re not in the same place now as we were. And what’s different is that we all use Welsh with him and that we use pictures. X is a totally different person. I’m so proud of him. The root of the blips in the past was to do with communication problems ... Communication is central to a good service.’

3.7 Language, therapy and mental health

3.7.1 One respondent describes the significance of language use in a therapeutic context, talking about an English-medium counselling service which she received. She refers to the counsellor and says,

‘She was lovely, but I felt unreal talking in English ... If she spoke Welsh, we would have reached somewhere else.’

3.7.2 There was a sense that using English to access her inner, emotional world failed to enable her to make the best use of the service being provided. There was a dislocation between the words being uttered and the experiences being explored. Consequently, she implies that the outcome in one language may have been different from the way it would have been in the other.

3.7.3 Another respondent describes the effect of the largely English-medium psychiatric services which his mother received over the course of several years; she died in November 2010.

‘She used to go to hospital but it was difficult for her to express herself in English. So, she used to feel that things weren’t moving as quickly as they should. She used to feel that they were talking above her and that they couldn’t have a dialogue with her. She had community (psychiatric) nurses who spoke Welsh and she used to say that they could listen.

‘After she died, I found scraps of paper around the house with English words on them, in preparation for speaking with the doctor. She used to ask me, what shall I tell them is the matter with me? I feel very bad? *Wy’n teimlo’n isel.*’

3.7.4 For her too, the words she needed to access in the therapeutic setting had no easy equivalent in English.

‘She had a lack of confidence too. She had this perception that the doctor had more education than she did.’

When the doctor was also English-speaking, this added to the sense of distance and inequality in their relationship, says her son, and this made it even more difficult for her to talk about her illness. Such was her sense of disempowerment.

‘Then she used to clam up and she wouldn’t say anything and perhaps that added to her illness. She just wanted stronger medication because talking didn’t work.’

3.7.5 Respondents also implied that in certain circumstances the lack of mental health provision in Welsh may give service users a detachment which distances them from the therapeutic process to some extent.

3.7.6 One parent comments on the way in which her daughter would conceal the truth and ‘... tell doctors what they wanted to hear.’ She poses the question whether a Welsh-medium service would have enabled her to express herself and to receive a diagnosis more readily.

3.7.7 A service user reflects on his experience as a long term user of mental health services and implies the element of displacement and possible control implicit in using his second language,

‘They don’t really have somebody’s true opinion. I can’t say how I feel. I can’t put it into words ... I’ve said more to you than I tell them. It’s safer not to say anything.’

He acknowledges that communicating in his second language may also lead to misunderstanding,

‘Everybody thinks that I’m ignoring them because I’m slow answering them. They get the wrong end of the stick. I’ve had that more than once.’

Occasionally, he says, ‘I struggle to understand what they’re saying. I don’t think that’s fair.’

3.7.8 Very few mental health service responses were received from north-west Wales. But one respondent from Ynys Môn comments positively about her experience as a psychiatric in-patient in Ysbyty Gwynedd. Welsh-medium provision was ‘very good,’ she says,

‘Everyone spoke Welsh. I could speak to them as if I was speaking with my family at home ... For me, being able to speak Welsh helps me get better.’

3.8 Welsh speaking staff – a hidden resource?

3.8.1 Respondents across each of the four priority groups spoke of a reticence on the part of health and social care staff to use their Welsh language skills.

3.8.2 One mother relates an experience with her health visitor, who despite being able to speak Welsh, was loath to say so.

‘She said, “*Sa i’n siarad Cymraeg iawn*”. But there was no reason for her to behave like this. Not enough value is placed on bilingual skills. There’s no training to build your confidence and to get used to using a more professional vocabulary (in Welsh).’

3.8.3 A respondent from south Powys makes a similar point,

‘A nurse came to the house to see my husband and I’d asked her over the phone the night before, “*Y’ch chi’n siarad Cymraeg?*” “Only a little bit,” she said. But she could speak Welsh as well as I can. If I’d followed what she said over the phone, I wouldn’t have spoken Welsh. And it made such a difference. You shouldn’t have to go cap in hand and ask, do you speak Welsh?’

3.8.4 A parent refers to her experience with nurses caring for her young son in a north-east Wales hospital,

‘When some nurses were caring for him they’d often say that they couldn’t speak much Welsh or that their Welsh wasn’t much good. But it isn’t the level of their skill and confidence which comes first in my opinion, and I’d have lots of interesting conversations with them, and I’d encourage them to use whatever Welsh they have and that it’s going to be good enough to make my little boy feel more at home in hospital.’

3.8.5 Several respondents suggest the need for employers to acknowledge and value Welsh language skills at all levels and to develop support systems to enable staff to further develop and strengthen their skills.

‘It’s a matter of raising the confidence of Welsh speakers and learners in the NHS. They need training how to use Welsh in their area of work. How to assess, for example, what words to use. If the worker feels more confident, they’re more likely to offer a service rather than everyone having to demand. Perhaps we need a certificate to place value on bilingual skills.

‘If you think of people answering the phone, if they lack confidence, they’ll be uncomfortable and reluctant ... If you can turn this on its head, you’ll be

raising confidence, the person will feel more comfortable and much more likely to offer Welsh.'

3.8.6 This person also said that staff have to be more 'proactive' in their use of Welsh and their offer of Welsh medium services when work with more vulnerable service users "... because they're not going to ask themselves."

3.9 The bilingual team

3.9.1 One parent makes the pragmatic point that

'We're not going to be able to have an ideal world where everyone speaks Welsh, but if the medical team has someone who's a Welsh speaker, that's a help.'

3.9.2 A mother in Cardiff describes her experience on a Neonatal Unit,

'English was the main language. In the Neonatal Unit there was one member of staff who spoke Welsh. Our physiotherapist spoke Welsh and she followed us and cared for our son at home as part of the neonatal outreach service. It was lovely being able to have this care through the medium of Welsh.'

3.9.3 Another respondent talks about the experience of taking her elderly mother to an outpatients' clinic and the value of having a bilingual nurse who is able to confirm in Welsh the advice given earlier by the doctor.

'We came out from seeing the doctor and the nurse said in Welsh, "*Trîwch rhain, te, a pheidiwch â chymryd y lleill.*" I'd like to see more of this kind of thing happening; it's a big help. Lots of the doctors don't speak Welsh but if the clinic nurse speaks Welsh, it helps. If someone can explain to you, you feel safer. The problem feels smaller, or at least you relax. In English

something can sound complicated but in Welsh you think, jiw, that's what it means.

'My mother's hearing isn't what it used to be. The message doesn't always reach the brain as well as it used to. So, having a nurse who can go the extra mile and make sense of the jargon is a big help.'

3.9.4 Whereas this respondent implies that the use of the bilingual team member may have happened unwittingly, reflecting the fact that she and her mother live in a relatively strong Welsh-speaking area where the workforce potentially may be better placed to reflect the number of Welsh speakers in the community it serves, another respondent in north Wales suggested that a more conscious and planned effort was made to ensure bilingual team skills. For example,

'There are lots of Welsh-speaking and non Welsh-speaking nurses on the children's ward and every effort was made to ensure that there was a nurse who was able to speak Welsh on the shifts.'

3.9.5 Another respondent picks up the theme regarding the need to plan more consciously for bilingual team working in the priority areas covered by this research. He speaks of children's services. But the same holds for other areas of practice too.

'It's important that someone on the children's ward speaks Welsh ... I know that it's difficult with shifts and that it's an extra consideration but we need to start planning in a practical way.'

3.9.6 This is pertinent across Wales, in areas with high densities of Welsh speakers as well as in other, traditionally more Anglicised areas where there are growing numbers of Welsh speakers in densely populated areas where their

needs may easily be overlooked, forming as they do, a lower proportion of the overall population.

3.10 GP Services

3.10.1 Respondents from parts of south Powys, Neath Port Talbot and Gwynedd refer to the way in which community based health centres may fail to reflect the profile of the communities they serve. In Gwynedd, one parent laments the appointment of a non-Welsh speaking GP in a community in which 88% of the population are Welsh speakers.⁶ She says that the GP has now acquired a certain amount of Welsh 'on the hoof' and that this is helpful in terms of being able to greet and break the ice with patients. With her young daughter, for example, the GP is now able to ask, for example, *'Ble sy'n brifo? Yr ochr yma? Dwi'n rhoi hwn fan hyn.'*

3.10.2 However, she suggests that in communities such as this, it would be preferable if key personnel were required to attend intensive Welsh language courses before they commence work. This may make it easier, she says, for both the health professional and the patient to establish their clinical relationship in Welsh or bilingually from the outset.

3.10.3 An older person in south Powys describes what she perceives as the reluctance of reception staff to use Welsh in her local health centre.

'I phone and speak Welsh and I ask, do you speak Welsh, and they say, not really. They can but they don't want to ... And you go into the surgery and you're in another country.'

3.10.4 If you happen to go into the surgery and speak Welsh at the reception desk,

⁶ Table KS25, 2003, Knowledge of Welsh, London: Office for National Statistics

'You feel a fool when you turn round and other people (in the waiting area) who are Welsh think that you're making a fuss. You have to turn round and face them ... I don't like going in there. I'd rather take the tablets and leave it there.'

3.10.5 Another respondent from Neath Port Talbot describes what had happened in his local health centre, saying that the only Welsh-speaking GP has been replaced by another who doesn't speak Welsh. Added to this, the new doctor shows little, if any, respect for the language, 'He doesn't even answer me when I say, *bore da*.'

3.10.6 Implicit in these comments, respondents suggest a failure to plan for use and sustenance of bilingual services in the delivery of primary care. They suggest that greater attention should be given to language skills at appointment; this may include making available intensive and function specific language skills training, as well as more support for health care staff at all levels to acquire a sounder awareness of language use in their work with patients.

3.11 Shifting frontiers – the growing needs of urban areas

3.11.1 Several themes became apparent in the evidence received from respondents in urban Wales, in south and south east Wales especially. Firstly, the gap between the growing numbers of Welsh speakers on the one hand and the scarcity of Welsh medium provision on the other. This is evidenced specifically in relation to children's services: health visiting, speech and language therapy, and the school nursing service.

3.11.2 A parent in Cardiff speaks on behalf of several respondents in relating her experience of speech and language therapy services. The non-availability of services, what is perceived as a lack of responsiveness on the part of agencies, and the long delay in receiving language-appropriate services, were all common themes in the evidence received from parents in Cardiff and surrounding areas.

‘Our son is eight years old now. But at 18 months when he wasn’t speaking, the alarm bells started ringing. We went to our GP and health visitor. Neither spoke Welsh but we accepted that in Cardiff.

‘But when it was a matter of having speech and language therapy for him, because speaking was the crux of the problem, we wanted a Welsh-speaking therapist ... We were totally desperate by the time we saw somebody. We were ready to take anyone. We had a little boy who needed the service. And when they asked, “Do you want a Welsh speaker because if you do, you’ll have to wait another six months,” we had no choice. As a parent you have to do the right thing by accepting the service. It’s not a choice; you’re going to take what’s available. You’re given the offer, but it’s not an offer.’

3.11.3 It is only during the last six months that the family has received a Welsh-speaking therapist. During the preceding six years it was considered necessary for them to receive the input of a specialist therapist because of their son’s Autistic Spectrum Disorder. The specialist service was not available in Welsh. They speculate about the possible impact of earlier Welsh-medium input,

‘He started making progress when he was five years old ... we don’t know whether that would have happened sooner with Welsh-medium input. You can’t complain because the service is being provided.

‘Individuals used to apologise, but the system didn’t recognise his needs ... the attitude was, we’ve apologised, so now we can forget about it.’

3.11.4 The evidence from parents tends to suggest that, on the whole, they may be more vociferous and assertive in challenging the gaps in service provision. For other user groups there is a sense that they suffer double jeopardy as

vulnerable, sometimes marginalised service users who speak a minority language in communities where there are often significant numbers, albeit low percentages of Welsh speakers. In such communities, their language needs are often neither seen nor heard.

3.11.5 This was seen very clearly in an interview with an older person with learning disabilities in Swansea. Brought up as part of a Welsh-speaking family in a village on the outskirts of Swansea, she now lives in a group home and attends a day centre. English is now the predominant language which she uses from day to day. She recounts how she used to be able to speak Welsh regularly with another person who attended the day centre. He has recently died. In her evidence she hints at a sense of being divorced from her language and community.

‘It’s nice speaking Welsh. It’s homely speaking Welsh ... It’s easier speaking Welsh ... It would make a *lot* of difference.’

3.11.6 Subsequent discussion with a member of staff suggested that the day centre has no provision for Welsh speakers. The local authority, it was said, states that services should be provided in the service user’s language, ‘if the service user asks for it.’ For vulnerable users, this level of articulation or ability to create demand appears to be an inappropriate base for service development.

3.11.7 A young man from a Welsh-speaking home, who uses learning disability services in Swansea and lives in a predominantly Welsh-speaking community in the Swansea Valley, says that he is proud of his bilingual skills, his ability to speak English and to teach a few words of Welsh to staff at the day care facility which he attends. In his evidence, it emerged that there is very little, if any, Welsh language provision for him at either the day care facility or the Further Education College which he attends. He says ‘... I’m the only one who speaks Welsh.’

3.11.8 His father poses questions about staffing and recruitment policies in both settings,

‘Do they invite Welsh speakers? Do they ask about (language) skills? It would be very nice if some of the staff spoke Welsh.’

Both he and another young woman with learning disabilities in south Wales had attended Welsh-medium primary and secondary education. But subsequently there appear to have been few, if any, ongoing Welsh-medium learning and development opportunities for either. This is at odds with the education provision available to other Welsh-speaking young adults in Wales who, for the most part, have the option of continuing Welsh-medium opportunities post 19.

3.11.9 The experience of these more isolated Welsh-speaking service users is contrasted with that of two young respondents with learning disabilities living in Ceredigion, one of whom has sheltered employment in a large and predominantly Welsh-speaking workplace in Aberystwyth, and both of whom live together in supported housing and are able to speak Welsh together from day to day. This example suggests the specific challenges facing social care providers in urban Wales in terms of trying to ensure that the more naturally occurring and perhaps ad hoc opportunities available to Welsh-speaking people with learning disabilities in parts of rural Wales are made available to service users more generally.

3.11.10 The irony for one set of parents is that they have been able to find outside of Wales a level of Welsh language awareness and provision for people with learning disabilities which they failed to find in Wales.

‘There’s a healthy attitude towards Welsh there. More often than not, Welsh speakers answer the phone ... It feels strange that X had to cross the border to receive services in Welsh for the first time in twenty years.’

They state that the college in Shropshire employs Welsh-speaking staff and runs a weekly club for Welsh students.

3.11.11 Respondents refer to a low set of expectations about Welsh-medium service delivery in areas with lower densities of Welsh speakers. For example, an older person refers to his regular eye clinic appointments in Rhondda Cynon Taf.

‘Nobody has ever asked about Welsh and I’ve never said anything. I’d prefer it of course if the service was in Welsh. It would be different if I lived in Bangor or Gwynedd. I don’t expect it in this part of Wales ... it’s different in the north of course.’

Born and brought up in north-west Wales, he describes himself as someone ‘who didn’t speak a word of English until I was ten. I still think in Welsh.’

3.11.12 According to an older person living in Newport,

‘There isn’t one doctor in Newport who speaks Welsh despite the fact that there are 13,000 Welsh speakers here, so 13,000 patients. This shows that there are more Welsh speakers in Newport than in Caernarfon but standards are totally different ... We need to start appointing some staff on a pro rata basis with the local Welsh speaking population.’

3.11.13 A parent in Cardiff articulates the disparity by saying,

‘Our example shows that the failure to provide Welsh medium health care discriminates in a very real sense against the most vulnerable in our

communities: children, older people, and patients. Our daughter didn't receive appropriate health care because she came from a Welsh-speaking home. The Welsh language has to be mainstreamed as an equality issue.'

3.11.14 A service user in Wrexham refers to his longstanding contact with mental health service providers. Over the years, he remembers being cared for by only two Welsh-speaking nurses during his first psychiatric admission to Denbigh in 1961. However, he now has the support of a Welsh-speaking support worker through a third sector mental health provider, 'She comes from Rhos and speaks Welsh like me.' Speaking of the significance of receiving services in Welsh, he says that

'... there's something warm about being treated in Welsh. You're freer to say how you feel in Welsh.'

3.11.15 Another mental health service user, also living in north-east Wales, describes the lengths to which he went in an attempt to secure Welsh-medium provision. Now 30, he says that he has received psychiatric services since his early adolescence but has never received any element of this in Welsh despite saying that '... Welsh is the language of all the family.'

3.11.16 Over the years, when he has broached the subject of receiving Welsh-medium provision, be it from a psychiatrist, social worker or support worker, he says that he has been told that this would be much easier if he lived in Gwynedd. And so, the last time he became unwell, he says,

'I went to Bangor. I wasn't well. I went to Bangor under the impression that I'd be able to see someone who spoke Welsh there. But after waiting there for three hours, driving me back to Glan Clwyd is what they did.'

Even if it may not be possible to receive a Welsh-speaking psychiatrist, he says, he would still value having some support in Welsh.

3.12 Losing language

3.12.1 Evidence provided by the families of older people suggests that the language profile of residents in care and nursing homes may be overlooked. This was summarised by one person whose elderly mother in her 90s has moved into private sector nursing care in Ceredigion, and by doing so ‘She’s moved from a Welsh to an English-speaking world overnight.’

‘When Mam starts speaking Welsh with them, they (care staff) say, “no, no, speak English with me.” It’s only English that Mam hears. It’s a frustration for me ... Now, she starts speaking English with me sometimes. She’s gone from having Welsh as her only language to being someone who speaks English first.

‘I took in a picture and word chart, with words like *cysgu, codi, ’molchi, cribo gwallt, sebon*. It had the picture and the words and it told you how to pronounce the word phonetically ... But I’m not sure now how much use they make of it.’

3.12.2 One of the saddest things, she says, is that English-speaking care ‘... can’t take Mam back to the old days, the only thing that she’s able to talk about really.’ As a farmer’s wife in rural Ceredigion, her world had been constructed through the language and culture of her immediate community.

3.12.3 Opportunities are missed, she says, as the entertainment laid on for residents tends not to be appropriate, linguistically or culturally, for people like her mother. For example, when the chaplain visits, they sing English hymns, and ‘... Mam doesn’t know the words.’ She sums up wryly, referring to the visit of a

saxophonist when one of the residents expressed her discontent, saying ‘... haven’t you got a record of Jac a Wil?’

3.12.4 She contrasts this with a local authority residential home where her mother lived previously. There, she says, the links with the local community were better developed,

‘... everyone knew one another; they used to have a Welsh service every Sunday afternoon. But this home could be in the middle of Birmingham or Manchester.’

3.12.5 Another family member sums up the implications of language loss for older people for whom Welsh has been their core, if not their only language. When you’re elderly and fragile and find yourself in unfamiliar surroundings,

‘It’s as if you’re plucked from your normal world and put into another almost surreal world where you can’t rely on the norms of daily life to sustain you. Receiving care totally through the medium of English just intensifies this sense of unfamiliarity.’

3.13 Language, assessment and care – the challenge of dementia

3.13.1 Carers and family members refer to the crucial role of language in caring for people with dementia. A carer talks about taking her relative for regular memory clinic appointments where assessments tended to be in English.

‘It was horrible. I didn’t want to go. I used to corner her. I had to pin her down. It wasn’t appropriate for us. I felt that we were just a number. There was no relationship at all. She used to become more agitated ... Because I was in the middle, I had to explain and they used to look at me as if I was deceiving them.’

She contrasts this with subsequent appointments with a Welsh-speaking psychologist,

‘She explains simply; she uses every day Welsh ... The diagnosis is the same but we feel different.’

The essential difference, she says, is that having a shared language and an associated understanding of culture has helped create a clinical relationship.

3.13.2 Other respondents refer to linguistically and culturally inappropriate assessment. For example, one carer says that his mother was asked to sing God Save the Queen as part of her memory assessment, suggesting that if she’d been asked for the words of *Hen Wlad fy Nhadau*, her response may have been different. And another relative recalls his father being asked to memorise an address in Guildford. His response, he says, may have been more precise had he been asked for an address in his native community in Tregaron.

3.13.3 Several respondents refer to the way in which language use can either agitate or placate the person with dementia. A daughter talks of the effect of this on her father,

‘There were two people who spoke Welsh on the ward and when one of these happened to be on duty, he’d be quieter. He used to sit down, whereas otherwise he used to parade around. It makes the condition a lot worse if you can’t communicate in your first language. If there weren’t any Welsh speakers on the shift, he used to be wild. He’d stare. His arms used to flay around.’

3.13.4 She speaks for other carers and family members as she explains the importance of language-appropriate care for her father. ‘It’s the last thing you learn which is the first to go with dementia,’ she explains. So, for her father - and

for other first language Welsh speakers for whom evidence was received - his English language skills were wiped out as his dementia deteriorated.

‘To try maintaining his self respect, it was so important for him to use and hear his own language.’

Without this, his frustration and agitation would increase and ‘We saw that language and care go hand in hand.’

3.13.5 Another carer refers cynically to the link between language, assessment and service delivery.

‘When I take X to be assessed, they ask (her) questions, and access to services depends on the level of your understanding of course. So, if you’re being assessed in English, as tends to happen, your assessment level will be lower and your access to services easier.’

‘X is still more fluent in Welsh. Putting sentences together is easier in Welsh. The words fail her in English; the sentence dries up.’

3.13.6 All these respondents refer to their experience of service delivery in rural west Wales. For all, there were gaps in Welsh-medium services and constant challenges for carers and other relatives anxious to maintain the dignity of users. The gap between the perceived needs of the user and the actual level of service available in a largely English-medium EMI provision in west Wales is summed up by this relative,

‘He’s like a caged animal. Often I have to go in to quieten him down, to soothe him. Because of his serious dementia he needs 1:1 care in Welsh.’

3.14 Language and Assessment

3.14.1.1 *Children's Services:* Parents in several parts of the country refer to difficulties in obtaining hearing and vision assessments in Welsh. One parent in Gwynedd refers to her experience of taking her young son to see an optometrist,

'She didn't have a word of Welsh. No idea. And she failed to assess him because she had no Welsh.'

3.14.1.2 Other parents describe the process of acting as a go-between and translating between professional and child. Such was the experience of this parent, also from Gwynedd, who takes her daughter for regular eye tests. It was a frustrating process for both child and professional, she says.

'I found it difficult and eventually I asked to be transferred to the clinic in Pwllheli thinking that specialists there may have a better understanding of the language issues because there's a high percentage of Welsh speakers in Pen Ll n.'

The onus for recognising language need and seeking out appropriate services was very clearly left to the parent; it was not recognised and acted upon on an organisational level.

3.14.1.3 Another parent refers to the risks implicit in translation; similar issues regarding the accuracy of assessment via translation were raised by several respondents. This is how she describes the process,

'She (the audiologist) asked a question, I translated it for X and then she relied on me to translate again for her. There was a lot of scope in that process for misunderstanding or misinterpretation ... I don't know whether it was a correct assessment or not.'

3.14.1.4 Parents in another part of the country refer to the experience of taking their daughter to their local audiology clinic between September 2007 and July 2009.

‘During this period we saw three doctors. The first doctor, I remember, asked things like, “Can you hear this in the front of your ear, at the back of your ear?” X, who will be seven in May, couldn’t understand him at all and I had to try translating.’

A year and a half later, the third doctor acknowledged their failure to assess the little girl in English and made arrangements for her to be referred to a Welsh-speaking colleague.

‘It was a waste of money and resources,’ say her parents, ‘We lost a year and a half; we were none the wiser and we were frustrated. We were in the dark.’

Since the intervention of the Welsh speaking doctor, they feel that things have moved. Subsequently, their daughter received appropriate tests, was fitted with a hearing aid and has started receiving additional support in school. For them, the Welsh-medium assessment was the turning point.

3.14.1.5 The parents of a child with learning disabilities in Ceredigion refer to the largely seamless language provision which they have received for their seven year old son. His mother refers to the relationship with his Welsh-speaking paediatrician, for example,

‘If he spoke English, he’d only be speaking with us. He wouldn’t have a relationship with X. He gets more out of X. He can assess him better. X doesn’t have any English.’

3.14.1.6 This has made it much easier for them to form a clinical relationship. She says that ‘He knows X and X knows him. That makes a big difference.’ She also refers to the value of having a Welsh-speaking speech and language therapist as well as a key support worker who speaks Welsh. As well as making for sounder assessment, she feels that

‘It’s a lot easier for us. I’m more fluent in Welsh. It feels more personal. You can talk about your worries.’

3.14.2 Health visiting services

3.14.2.1 Parents in many parts of the country refer to not being able to receive Welsh-medium health visiting services. For a parent in Llanelli, this raised issues about the quality and accuracy of assessment. For example,

‘Our son only had one language until he started school ... This caused problems. He didn’t understand anything the health visitor said to him. So, in terms of assessment, it was a fake assessment, with the health visitor relying on what I told her ... The child isn’t given fair play in terms of his assessment. He isn’t comfortable. I have to translate backwards and forwards. Really, you have to rely on the parent’s ability to spot problems.

‘We now have a daughter who’s 27 months. When I went to see the health visitor for her two year assessment, I explained to her that I was worried about her speech. Her response was, “Yes, but she’s learning two languages. That usually causes a bit of delay” ... When I tried explaining that we were only giving her one language, Welsh, at the moment, she was flabbergasted. So, I had to insist on her being referred for speech and language therapy. I was the one who was assessing, not her.’

3.14.2.2 Similar themes are picked up in the evidence from another parent in Conwy who was also expected to translate during her daughter's health visitor assessment.

'I could have given the health visitor any answer and she wouldn't have known whether I was misleading her or not. Of course, I didn't but what's the point of testing or assessing a child when the professional can't do the assessment correctly because they don't speak the same language?'

For this parent, the process raises questions about the accuracy of the assessment, with her daughter's assessment level remaining unchanged between one annual assessment and the next. She summarises,

'I was quite disappointed on two fronts. Firstly, because there wasn't a Welsh-speaking health visitor available (and from what I understand, there isn't a Welsh-speaking health visitor in our area since the only one retired in 2008). And secondly, because she assumed that our daughter would speak English.'

3.14.2.3 For both these parents, and for others who provided evidence, their experiences raise issues for them around the need to recruit and train more Welsh-speaking health visitors; the continuing professional development needs of health visitors in relation to understanding the process of language acquisition for young, monolingual children in Wales; and the allocation and management of health visiting resources - on a community rather than a practice basis - in order to make better use of the existing Welsh-speaking workforce, according to one parent.

3.14.3 Safeguarding services

3.14.3.1 A respondent from a south Wales local authority refers to his experience as the parent of a baby who became the subject of a safeguarding investigation.

‘After the baby was born, the Social Services Department came on the scene. It became clear that my partner had problems in the past. The baby had to go on the Child Protection Register ... Everything in our relationship was in Welsh. But in the core group meetings when we were working on the Care Plan, everything was in English. To start with, I didn’t say anything. It was obvious that we spoke Welsh because we spoke Welsh in the meetings. It was a difficult time for me and I didn’t ask about Welsh to kick off with. A few months had gone before I raised it. I explained that we needed to be able to talk about intense, personal things in Welsh. But they (the social worker) became defensive and said “I don’t speak Welsh”. I’m not asking you to speak Welsh, I said. But I want you to consider us and provide for us.’

3.14.3.2 This parent implies that the worker had no clear access to agency procedures or guidance which would have enabled her to respond to the parent’s concerns objectively. She was left bare, having to respond to his comments subjectively and defensively. He goes on to make an important link between the language of assessment and the language of the relationship or circumstances being assessed,

‘The things we were trying to discuss in the meetings had happened in Welsh – the feelings, everything in Welsh. The situation was the most difficult one for me ever. My English is OK but when something has happened to you in Welsh – the feelings, the arguments all in Welsh, and you have to do it all under a lot of pressure, it’s terribly difficult in English.’

3.14.3.3 Talking of the assessment process itself, he implies that not only would it have been easier for him in Welsh, but that this may have also offered a sounder understanding of the dynamics of his relationship and the implications

for his child. It would also have given him an element of control in an otherwise disempowering situation,

‘I would have preferred doing it all in Welsh. I think it would have been easier ... I could have opened up more easily. Discussed things more easily. Whichever language was used, the feeling that people were coming into my home, my family, was difficult. But if they could have spoken the language which I’d chosen, things would have been a bit less intrusive.’

3.14.4 Understanding and Being Understood

3.14.4.1 For an older person being admitted to hospital as an emergency, the ability to speak Welsh with the ambulance crew and the nurse in Accident and Emergency was important for her. She felt better able to explain the exact nature of her pain in Welsh, thus making a diagnosis easier, she feels.

‘It was easier to explain in Welsh. Although I speak English with my husband every day, you can explain how you feel more precisely in Welsh. I could get hold of the exact word. It wasn’t a pain, but a *pigyn* and I could say exactly where it was beneath my rib. And I could also say that I felt *chwil* ... Pain is something which affects a wider area, but a *pigyn* is in one place. And the only word I’d have for *chwil* would be faint and that isn’t the same thing.’

3.14.4.2 Conversely, for a carer accompanying her relative for a psychiatric assessment, the use of language proved to be a barrier to understanding and assessment.

‘It wasn’t just the doctor’s English which was hard for him. It was the kind of English he was using. He had a checklist and he kept asking one question after the other. “What is your alcohol intake?” “What’s he

asking?” he'd say to me. “He's asking how much you drink” ... Then, he asked, “Are you feeling suicidal?” And I had to say to him, he's asking why you want to do away with yourself?’

There was a gulf, with neither understanding one another. Rather than language being a therapeutic tool, it served as a barrier. And according to the carer,

‘There was no relationship there at ... I could see him closing up. And by the end of it all, all we had were tablets. We didn't go back. There was no point.’

3.14.4.3 Similar blocks arose for a family taking their young son to be assessed by a physiotherapist, with both family and professional resorting to their second language.

‘It was difficult for him to explain what he wanted us to do. X was becoming frustrated. He didn't want to be there. There was frustration all round. He couldn't express himself and X couldn't understand and X didn't want to go to see him (again) ... It was all because of language, because we were having difficulty understanding what we were supposed to do with X ... If we couldn't understand him properly, the instructions we were giving X were wrong and he (the physiotherapist) was saying, “no, no, not like that” ... and we stopped going.’

3.14.4.4 Another respondent suggests that assessment in one's second language also runs the risk of misunderstanding or misinterpretation, albeit in more subtle and less literal ways. She reflects on her experience as a mother,

‘When someone asks your Welsh-speaking child questions in English, lots of things can happen. One thing is that the child can turn his head and look at his mother. In some circumstances this can be interpreted, or can

mean that the child is afraid to speak for himself, and is looking for permission to say something in case he has a hell of a row for saying something out of place after going home.'

She goes on to talk about her experience,

'To help him understand, I'd translate what the doctor or nurse had said and would then translate for the doctor what X had said ... It's possible that they may not be able to pick up what they should if there was something really wrong, or even worse for us, they could pick up something which doesn't exist.'

'The other thing that's possible is that I come across as one of those overpowering parents who speak for her children. If the conversation was in Welsh, I'd encourage X to respond to the person asking the question. That would create a very different impression of me as a parent. If the doctors saw me as an overpowering mother, that could mean that they'd see me in a different light and treat me differently, more negatively perhaps.'

3.15 Language and Relationships – more than words

3.15.1 For many respondents, the use of one's preferred language is often powerful in terms of creating affinity and forming closer professional relationships. This is how an older person describes her relationship with her GP.

'When you're ill, speaking Welsh makes a difference. There's closeness there ... Here's an example for you now. I wanted coated aspirins because the others make me ill. Now, I could tell Dr. X light heartedly, you're either going to give me the coated ones or I'm not going to take them at all! With

Dr. X I could laugh about it ... I wasn't complaining. I could strike the right note in Welsh.

'When you go to see an English-speaking doctor, you tend to feel that they're up here. You can reduce the distance when you speak Welsh. You come to the same level. The atmosphere changes completely ... It all comes out then.'

3.15.2 For an older person admitted to hospital for surgery, the role of a Welsh-speaking ward sister was significant.

'The sister who received me onto the ward spoke Welsh. That was so nice; one feels more at home. It made me feel so much better ... And I told her, "I look forward to seeing you after the op. tomorrow," and she said, "Oh, sorry. I won't be here tomorrow." She told me later, "I saw your face drop."

3.15.3 Another relative reflects on his mother's relationship with the community psychiatric nurse who visited the family home to offer support because of his father's Alzheimer's.

'My mother said that he was nice enough but I think that she would have had more use from the service if he spoke Welsh.'

He implies that the English-medium service lacked the linguistic and cultural relevance which would have helped his mother form a professional relationship with the nurse.

Conversely, when they received the support of a volunteer support worker,

‘She spoke Welsh and came from the same kind of background. My mother could trust her to take my father out. My father doted on her too.’

3.15.4 For the mother of a young man with disabilities, the ability to receive services in Welsh is vital not just for her son, but also for her.

‘In Welsh, I can talk about experiences and really personal things. It’s easier to do that in Welsh. The flow isn’t the same in English. You have to translate, especially when you’re talking about something which is so important to us as a family.’

She suggests that Welsh is the language of her emotional life and the language which lends itself best to discuss family relationships and issues which are rooted in it.

3.15.5 For one carer, it’s a straightforward matter of making the best and most productive use of time, saying that ‘When you go to see the doctor, you only have five minutes.’ It’s therefore important, she says, to be able to communicate in the language which best equips you to get to the nub of the problem as quickly and effectively as possible.

3.15.6 One parent describes her experience of being escorted by a Welsh-speaking nurse when her young son was diagnosed with leukaemia.

‘I clicked with her immediately. Her roots and upbringing were within 10 miles of where I’d been brought up. So she knew where I came from, not just in terms of geography but linguistically and culturally. I can’t begin to describe how vital she was in giving me the confidence to believe that I could care for X. I trusted her implicitly and I knew that she was talking with me in a way that showed that she understood me.’

3.15.7 The second significant relationship she describes is with another nurse on the ward in Alder Hey Hospital where her son was being treated. As a result of steroids, he was beginning to display behaviour that she wasn't accustomed to. And in the throes of trying to decide how best to handle this, she found herself talking with another Welsh-speaking nurse.

'Now in Liverpool one wouldn't expect to come across that many staff able to speak Welsh. But on this Saturday night, one of the night staff came in through the curtains around the bed and said in Welsh, "They've told me that you speak Welsh and that you're with me tonight.

"Oh, look at him," she said, looking at X and seeing him sleeping quietly. "Oh, don't mention it," I said, "I had a hell of a problem with him earlier on. I've had to stand up for myself to tell you the truth and I've had to tell him how things are going to be." "Well, good for you," she said, "There are plenty of children who leave here as really unpleasant so and sos because they've been able to do just as they wish, just because they're ill. You stick with it, and he'll be OK, you'll see."

And she goes on to say,

'Despite the difference in our age, our generation, our life experiences and professional background, there was a rapport with this nurse from the first few seconds which made me feel that we'd always known one another. It was as if our relationship had formed in a matter of minutes, what had taken weeks, months, if at all, with others on the ward. I'm not suggesting for a second that everyone who speaks Welsh click together and that this is the only factor which is important in dealing with people. Neither am I saying that the reverse is true and that it isn't possible to have rapport unless you speak the same language. What I am saying is that I'm

convinced in this situation that the fact that she spoke Welsh was really crucial.

‘She was a bridge for me between my sick child and the medical team who were going to be treating him. She gave me the confidence to ask his consultant about the best way for me to handle X. I don’t think that I’d have been able to have had that conversation had she not given me confirmation that I was on the right track.’

3.15.8 If, for people such as this parent, communication is easier and the process of forming professional relationships is facilitated more in one language than the other, the impact of language-appropriate service delivery is likely to be much greater for people for whom communication in a second language is an even bigger struggle. This is the point made by the brother of a person with learning disabilities, now deceased, for whom Welsh-medium services were lacking.

‘For me personally, I’d want my services in Welsh. I feel differently. I feel a lot more comfortable – I understand what’s going on. In English, I think in Welsh and translate. It’s not the same. For X (his brother) it was much more difficult. It was tough for him.’

3.16 Delays in service provision

3.16.1 Respondents often refer to the experience of being told that services are either not available in Welsh or that they may face delays in receiving a Welsh-medium service, as was seen in 3.14.1.4 above, for example. This is also described very clearly by the relative of an older person with dementia living in Pembrokeshire. Because of her deteriorating health, the family made a referral for an occupational therapy assessment. They had stated when making the referral that a Welsh-medium assessment was needed. They found themselves having to wait, and

‘After several phone calls, we were offered a translator but I wasn’t happy with that ... We waited for several months – phoning and asking what was happening and being told that there was nobody available ... We were again offered a translator – and eventually, a Welsh-speaking social worker from Ceredigion ... there wasn’t one Welsh-speaking occupational therapist in the whole of Pembrokeshire or Ceredigion. In the meantime, a few days before the social worker was due to visit, my mother fell and broke a bone, a really painful fracture which meant that she had to spend months in hospital in Haverfordwest ... If we’d been able to have the service we’d asked for without having to wait and wait, perhaps Mam wouldn’t have fallen, as she didn’t have a walking frame at the time.’

3.16.2 This left the family with the impression that their request for a Welsh-medium assessment was seen as

‘... odd, unusual, unreasonable. Or that was the feeling we had. And my mother suffered a lot of hardship as a result. If the services had taken the request seriously, they’d have found a way to sort the problem much sooner.’

3.17 Service delivery which relies on the assertive users or carer

3.17.1 Many users and carers across each of the four priority groups say that Welsh-medium services are delivered on the basis of demand rather than need. This is how one mother puts it,

‘I asked for a service in Welsh. That isn’t common. Welsh speakers although wishing to have (a service in Welsh), don’t make that clear enough to start with.’

She describes herself as an assertive Welsh speaker, and therefore not necessarily representative of Welsh speakers as a whole.

Speaking of her young daughter, she says,

‘Vulnerable people like X can’t say. So, they have to rely on an assertive family. And not everybody’s going to complain ... The problem is that Welsh speakers don’t ask. We treat the health service with humility, being thankful for everything we have.’

3.17.2 Several respondents explain how they had found themselves having to ask, and ask again very often, for services in Welsh. One carer relates how she contacted her local social services department to ask for an assessment of her elderly relatives. She asked for an assessment in Welsh. Despite this, the assessment visit was made by a non-Welsh speaker. Therefore, the carer again contacted the department, and on the second occasion the assessment was undertaken in Welsh.

3.17.3 One respondent reflects on her experience as the parent of a child with disabilities.

‘Everything’s a struggle for children with disabilities, not just Welsh. Keeping up your steam is difficult and sometimes your energy flags.’

The most recent issue for this parent has been the lack of Welsh-medium respite care for her son. But she is now hopeful that a suitable family may be available.

3.17.4 Another carer says how she had to stress the need for a Welsh-medium service for her mother when she approached a large third sector provider on her behalf,

'I had to ask for someone who spoke Welsh. They didn't have any local volunteers (in Ceredigion) who spoke Welsh. I had to press them and we had to wait for a Welsh speaker. But it made such a difference.'

3.17.5 A few respondents suggested that it may be increasingly difficult to create this level of demand once they start receiving services and getting to know individual providers,

'You don't want to complain and upset people because we're still in the system. The individuals are great. But the system itself makes no provision for Welsh.'

And another relative says,

'What's unfortunate is that we feel grateful if we have someone who speaks Welsh, as if we were having some great favour.'

3.17.6 The parent of a mental health service user describes the intense difficulties they faced during a period of acute inpatient treatment. There were no Welsh-medium services available to them as a family and as a result,

'It crossed my mind as to whether I should draw attention and try to do something about this. But I was using all my strength to keep things going without going after something political ... It was a terribly traumatic time for us and to be perfectly honest, worrying about rights went to one side. But it was difficult because we were discussing things in our second language. X may have expressed more in Welsh and it may have been easier to get a diagnosis sooner.'

But to have asked for a service in Welsh in these circumstances would have felt like a political act for this parent. And this felt unworthy and inappropriate at the time.

3.17.7 For another parent, as well as a general reluctance to complain, there are pragmatic issues which also have a bearing,

‘We don’t complain - we take the children out of school, wanting to get to the root of a problem. You also take time off work and we just want to keep the appointment and make the best of it.’

3.17.8 Users and carers may also find themselves in disempowering circumstances which means that demanding or complaining is difficult, if not impossible. For example,

‘Usually, I demand my rights. But in this situation, it was a new situation for me. I’d just found that the mother of my child had serious problems ... I’d lost all my power as a service user. I wasn’t going to demand my rights. People were coming into my life. I had no power. It’s hard enough anyway, asking for a form in Welsh or something. But in this situation it was completely impossible.’

3.17.9 For many who lack a voice of their own, parents and carers are vigilant and attentive. This is expressed by the daughter of a person receiving residential care,

‘She’s lucky that we can speak for her. There are some people there with no family and they don’t have anybody to explain things ... I go every day to check that she has everything she’s supposed to. I try doing simple little jigsaws with her and I ask “*pa liw yw hwn, mam?*” But they can’t stimulate her like that.’

3.17.10 For some families, the will and energy needed to express a demand for Welsh-medium services can only be sustained for a certain period of time. This is articulated by the parents of a young man in his twenties with learning disabilities, living in Pembrokeshire. They say that they have never had a Welsh-speaking social worker. The same is true of other services too, they say, with the exception of one visit from a Welsh-speaking educational psychologist and the involvement of a Welsh-speaking speech and language therapist for a short period.

‘At times, we’ve been frustrated and angry. But by now, our expectations of the service of the county council is so low, nothing surprises us. We don’t expect any service in Welsh from the council to tell you the truth.’

3.17.11 For another parent in north Wales - who in 2004 complained about the lack of Welsh medium orthoptic assessments for her older child - the prospect of complaining again is more than she can contemplate, now that she sees that nothing has changed and that she faces a similar set of issues with a younger child. She states clearly, ‘I don’t want to go through that again.’

3.17.12 Service delivery premised on the concept of demand rather than need is unlikely to produce significant improvements in Welsh medium delivery. The low expectations of the majority of Welsh speakers as speakers of a traditionally marginalised, minority language as well as an underpinning reluctance or inability on the part of often disempowered individuals to complain about health and social care services, militate against the ability to effectively challenge the services being delivered.

3.18 Messages for the Welsh Assembly Government

3.18.1 All respondents were asked to consider the changes they would like to see implemented in the way in which Welsh-medium services are developed and

delivered. Several suggestions were made relating to workforce development, valuing bilingual service delivery on both an institutional and individual level, and building into administrative and professional systems ways of identifying language needs and making intelligent use of data.

3.18.2 More specifically, respondents mentioned the need to vigorously recruit Welsh speakers into the health and social care sector. For example,

‘I think that more money is needed to draw more Welsh speakers into being psychologists and social workers. Financial incentives are needed, like the ones that are available to attract maths and science teachers, for example. And another thing that’s needed is more status for (home) carers, the people who do the spade work.’

3.18.3 Parents talk about the scarcity of Welsh-speaking speech and language therapists and one parent expresses a sentiment shared by others too,

‘The Welsh Assembly Government should allocate funding to increase the opportunities for training bilingual speech therapists and make available funding to create jobs for them.’

3.18.4 Others refer to the importance of gathering data at the point of referral and using this to guide appropriate interventions. Respondents argued that this would help make better use of resources; improve the service to the user; enhance satisfaction with the service, and reduce the possibility of inaccurate assessments. Parents suggested that young, monolingual Welsh children should be offered a Welsh-medium service without parents being expected to ask for this.

3.18.5 Other respondents referred to the importance of auditing the level of language skills in the workplace and then providing appropriate training to

enhance skills and confidence. It was suggested that for many it is a matter of recognising and valuing their latent Welsh language skills and supporting their use of the language. Many respondents suggested that a little Welsh may often go a long way.

3.18.6 Language awareness was also referred to and according to one respondent, this may help key personnel to understand

‘... how people use language. The easy thing for agencies now is to become self-defensive and to forget all about it.’

3.18.7 Several referred to the practical but important cue given by those wearing *laith Gwaith* badges. This enables Welsh speaking users to identify Welsh speaking providers, without opportunities being lost and resources being hidden.

3.18.8 Finally, a carer mentioned how valuable it would have been for her when she was looking for a suitable residential home for her mother, if providers had available information about the number of staff members able to speak Welsh.

4. Conclusions

4.1 In its focus on the experiences of service users and carers in the four priority groups identified, the research has affirmed the link between language and care. It draws on examples which imply that the quality of care to vulnerable users may be compromised by the failure to communicate in their first language. The examples provided in relation to residential and domiciliary care provision for older people illustrate this. The crucial role of language as an assessment and diagnostic tool is also addressed and the reliance on translation, using family members to convey information between service user and professional, is seen to be fraught with problems which may affect the nature of the assessment undertaken. For users and carers, the ability to communicate in their preferred language is seen to have an effect on the formation of clinical and therapeutic relationships. This may be particularly significant in relation to the delivery of psychiatric and therapeutic services.

4.2 Respondents imply that Welsh medium service delivery in many areas is often haphazard and seldom planned. Individual members of staff at many levels lack the confidence to use their Welsh language skills in a professional context; employing agencies may fail to acknowledge and place value on these skills, and individual language skills remain hidden and untapped as a result.

4.3 The prevailing culture within the health and social care sector in Wales appears to be premised on the expectation that service users or carers will identify the need and create the demand for Welsh-medium services, rather than on the basis that service providers have a duty to offer and provide. For many vulnerable and disempowered individuals in the priority groups covered by the research, the ability to articulate their need and create demand is beyond their grasp. They are often reliant on carers and family to do this for them. Many have no such support. The most vulnerable and isolated service users therefore need access to services and underlying systems which are robust and reliable enough

to recognise their language needs and respond appropriately. Respect for the dignity of individuals requires this.

4.4. Such a fundamental shift calls for systemic changes in attitudes, procedures and workplace practices which may include the following:

i) The language use and preference of service users in each of the four priority groups is identified at the first point of contact and used to inform appropriate interventions.

ii) Language related information then accompanies users as they proceed through the system and is flagged up at each new referral point.

iii) Data gathered at the first point of contact contributes towards the process of establishing unmet need in relation to language-appropriate provision. This data is then used to inform agencies' Welsh language skills strategies as well as their workforce development and training strategies, with a view to developing support systems which enable staff to develop and strengthen their language skills and thus extend the range of services available to Welsh-speaking service users.

iv) Monitoring and ongoing quality assurance are needed both internally and through external auditing and inspection mechanisms to ensure the ongoing development of real changes in the Welsh-medium services available.

v) Language awareness training is seen as a fundamental building block in developing and sustaining sound and sensitive workplace practices.

Annex 1: Sample copies of publicity material

1a. Press Release

PRESS RELEASE

Date: 17 January 2011

The Experience of Welsh Speakers in Health and Social Care Services – Important Research

The Welsh Assembly Government and the Care Council for Wales are keen to hear from Welsh speakers about their experience of health and social care services through the medium of Welsh. And they have commissioned a team of researchers from the Welsh Centre for Language Planning to do the work.

“The results of this important research will be used to identify priorities,” says Gwenda Thomas AM, Deputy Minister for Social Services, “They will drive forward improvements to services by the end of this year.”

Researchers are keen to speak with patients, service users and carers to find out more about their experience. Was it easy to receive a Welsh-medium service or were there obstacles? What effect did this have? Were they happy with the service they received or do they have suggestions about ways of improving services?

“For many people such as children, older people, users of mental health services and others, Welsh language services are a matter of *need* rather than *choice*,” says the Deputy Minister. “Very often, it’s only through the medium of their first language that they can be treated effectively.”

And this is why researchers are keen to hear about experiences relating to children (including speech and language therapy), older people, people with mental health problems (including dementia), and people with learning disabilities.

“We wish to hear from users and carers in these areas and hope very much that they will contact us,” says Elaine Davies, who leads the research team. “People will be able to take part in the research through face to face interviews or through pre-arranged phone interviews and they are also welcome to submit written evidence – whatever suits them best. We hope very much to have responses from people right across Wales. All information will be handled with complete confidentiality.”

This is an important opportunity to influence policy and to strengthen Welsh medium health and social care services. “I welcome this research and I urge Welsh speakers to take part”, says Gwenda Thomas “It’s very important that we listen to the voice of health and social care service users and that we understand their need for Welsh medium services.”

Note for editors:

For further information, please contact either Elaine Davies on 01239 711668 (elaine.davies@iaith.eu) or Elin Mair on 01239 711668 (elin.mair@iaith.eu)

Research timescale:

Open invitation to take part in research: January 17 – February 4

Research interviews: February 4 – March 11.

End of Press Release

Annex 1b. Letter sent to local papers

Dear Sir / Madam,

Do your Welsh-speaking readers have any experiences of health or social care services which they may like to share, be they positive or otherwise?

The Welsh Assembly Government is keen to hear from them and have commissioned a team of researchers from the Welsh Centre for Language Planning to do the work.

Researchers are keen to speak with service users or carers who are happy to talk about their experience. Was it easy to receive a Welsh-medium service or were there obstacles? What effect did this have? Were you happy with the service you received or do you have suggestions about ways of improving services?

We would very much like to hear experiences relating to children, older people, people with mental health problems (including dementia), and people with learning disabilities.

To find out more about the research and how to take part, your readers are very welcome to contact Elaine Davies at the Centre for Language Planning on 01239 711668 or elaine.davies@iaith.eu). All contacts and contributions will be handled confidentially.

I look forward very much to hearing from anyone who may be interested to take part by Friday, February 4.

Yours sincerely,

Elaine Davies,
(on behalf of the research team).

Annex 2: Number of responses by geographical area

Children	Carmarthenshire	1
	Cardiff	5
	Ceredigion	4
	Conwy	1
	Denbighshire	2
	Gwynedd	3
	Rhondda Cynon Taf	1
		17
Older people	Anglesey	2
	Cardiff	1
	Carmarthenshire	1
	Ceredigion	7
	Denbighshire	1
	Neath Port Talbot	1
	Newport	1
	Powys	1
		15
People with mental health problems (including dementia)	Carmarthenshire	2
	Ceredigion	3
	Conwy	2
	Pembrokeshire	1
	Vale of Glamorgan	1
	Wrexham	1
	10	
People with learning disabilities	Ceredigion	3
	Denbighshire	1
	Gwynedd	1
	Pembrokeshire	1
	Rhondda Cynon Taf	1
	Swansea	2
	9	
	Total	51

Annex 3: Participants' Letter and Consent Form

Dear

The experiences of Welsh speakers in health and social care services

Many thanks for your readiness to consider taking part in the research into the experience of Welsh speakers in health and social care services.

This letter aims to give you more information about the research as well as an indication of the kinds of questions we would like to discuss with you. It includes a consent form which enables you to confirm your readiness to take part.

The Background:

We are doing the research on behalf of the Welsh Assembly Government and the Care Council for Wales with the aim of gathering together the experiences of Welsh-speaking service users and carers.

The research stems from the work of the Welsh language Task Force, chaired by Gwenda Thomas, Deputy Minister for Social Services. Linked to this, a sub-group has recently been established to develop a *Strategic Framework* to promote the use of Welsh in health and social care. As part of the process of developing the Framework, the Welsh Assembly Government is keen to consider the experience of users and carers and to have a clear picture of current Welsh language provision. This information will be used to inform the content and direction of the new *Strategic Framework*. The research therefore offers an opportunity to influence the development of services over the next few years.

The Research:

The research focuses on the experience of the following groups:

- children (including speech and language therapy)
- older people
- people with mental health problems (including dementia)
- people with learning disabilities.

The consent form accompanying this letter asks you to identify the group to which you are linked and asks whether you are taking part in the research as a service user / patient or as a carer.

You may contribute in any of the following ways:

- face to face interview
- phone interview, or
- by submitting written evidence, either via e-mail or by letter.

Should we receive several responses from people living in the same area, it may be possible to arrange a focus group with an opportunity for those taking part to share their experience, on the condition that everyone is happy with this approach.

You may choose whichever method feels most comfortable for you and use the attached form to state your preference.

Having gathered all the information, I will be asked to prepare a report for the attention of the Welsh Assembly Government and the Care Council. The report will summarise the main points raised by those contributing to the research and, most importantly, it will summarise the experiences, comments and recommendations of all those who will have taken part.

Having said this, it is important to emphasise that all the information you share with me will be handled anonymously. We are very anxious to ensure confidentiality at every step of the process.

The Research Questions:

After receiving your completed consent form, I will send you a full list of the questions to which I would like you to respond. This will give you the opportunity to gather together your thoughts and prepare a little before submitting your evidence.

As already mentioned, we are keen to hear of your experience either as a patient / service user, or as a carer. You are welcome to refer to positive experiences as well as those which may have been less satisfactory.

For example,

- Did you find it easy to receive a service in Welsh or were there obstacles?
- If you encountered difficulties, what exactly were they?
- What effect did this have on you?
- If your experience was positive, what exactly were the strengths?
- If you were dissatisfied, how could the service have been delivered to you differently in terms of language? What effect may this have had?
- Based on your experience as a service user or carer, what are the main messages which you would like to convey to the Welsh Assembly Government as they set about improving the provision of Welsh medium services in health and social care?

Finally, I would like to thank you for your willingness to take part in the research. It offers a valuable opportunity to share your personal experience and to influence the development of Welsh-medium provision in health and social care over the next few years.

I would be grateful if you could spend a couple of minutes completing the attached form and returning it to me in the prepaid envelope.

If you have any questions which you would like to discuss before returning the form, please do not hesitate to get in touch.

I look forward very much to hearing from you.

Yours sincerely,

Elaine Davies
Researcher

The experiences of Welsh speakers in health and social care services

1) Personal Details

Name:

Address:

.....

.....

e-mail

Phone.....

2) Interest Groups

Please tick one of the boxes below to identify which of the following groups you represent:

Children

Older people

People with mental health problems (including dementia)

People with learning disabilities

Please indicate whether you are responding as a:

Service user / Patient

or as

Carer / Family

3) Preferred way of taking part in research

Please indicate how you would like to take part in the research by ticking the appropriate box:

Face to face interview

Phone interview

Providing written evidence. If you tick this box, please identify whether you wish to submit information:

by letter

by e-mail

Please note

If several individuals respond from the same area, it may be possible to consider arranging a focus group. This would offer an opportunity to contribute to the research by sharing your experience with other individuals in a group discussion.

I would be grateful if you could tick the appropriate box to indicate whether such an arrangement would be acceptable to you.

I am happy to take part in a focus group discussion.

I do not wish to take part in a focus group discussion.

4) Consent

I have read the attached letter and am happy to take part in the research. I understand that my experience and comments may be included in the research report which will be submitted to the group established by the Welsh Assembly Government to inform the development of a *Strategic Framework* for the Welsh language in health and social care services.

I accept that any such comments will be presented anonymously and that my evidence will not be used for any other purpose.

Signature

Date.....

Data Protection Act 1998

IAITH cyf. are registered under the Data Protection Act 1998. Your personal details will not be shared with a third party and will only be used for the purposes of communication in connection with this research project.

Thank you for completing this form. Please return it in the enclosed prepaid envelope to Elaine Davies at IAITH: the welsh centre for language planning as soon as possible.

Diolch o galon.

Annex 4: Research Questions

As you prepare your research evidence, you are welcome to share all kinds of experiences – positive experiences as well as others.

- 1) Please describe the service you would like to discuss.

- 2) What was your experience and what exactly happened in relation to the use of Welsh and English?

- 3) What effect does this have? For example, in relation to:
 - assessing your needs
 - the service you receive
 - the care you receive

- 4) How do you feel about this??

- 5) If you find this unsatisfactory, how could the service be provided differently in relation to language? What would the possible effect of this be for you?

- 6) Based on your experience as a service user, what are some of the messages which you would like to give the Welsh Assembly Government about ways of improving the delivery of Welsh medium services in health and social care?

Diolch yn fawr