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Developing Local Services

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Developing local services: Families and *'Valuing People'*

"In the same way that it is emphasised that adults with intellectual disabilities are people first, so care givers must be considered people first and consideration given to their full identity and multiple roles."

IASSID & WHO (January 2000.)

"Carers feel strongly that they have a lifelong responsibility for their sons and daughters. They want to be treated as full partners by public agencies."

(*'Valuing People'* DoH. 2001.)

"A real cause for concern and anxiety is that many parents of (the) learning disabled... face difficulties in finding the right care, health services, education and leisure opportunities for their sons and daughters. At best they can feel obstacles are constantly being put in their way by society. At worst they feel abandoned by the rest of us."

Tony Blair – *'Valuing People'*

Why families matter

- The majority of men and women with learning disabilities in this country are supported in the community by their families. Even when people with learning disabilities leave home it does not mean they stop being a valued member of their family network.
- Families are the only people who will have a continuous relationship with the person with a learning disability from childhood to adulthood. Families, therefore, have an important and unique contribution to make to discussions about services for the family member they support, as well as contributing to broader discussions about local learning disability services. This contribution needs to be acknowledged, valued, listened to, and acted upon.
- Families often describe their relationship with services using the language of war. Families describe themselves as war weary – fed up with battling – having to fight for every little thing. The research, *'In Their Own Right'* (Robinson & Williams. 1999.) found that many family carers said they found their relationships with services more stressful than any other aspect of caring for their learning disabled son or daughter.
- Family carers of people with learning disabilities have not always been well served by mainstream carer's initiatives. Research has shown they are not always accessing their right to a Carer's Assessment, and when they do it does not necessarily lead to getting the support they need.
- The report, *'Family Matters: Counting Families In'* (DoH. 2001.), was published alongside the White Paper, *'Valuing People'* and catalogues many of the concerns expressed by family carers of adults with a learning disability. Rob Greig, one of the architects of the White Paper, has talked about *'Valuing People'* as representing an attempt to create a 'new deal for families'.
- So, it comes as no surprise that ensuring families get the right sort of support is given high priority in the White Paper. **Objective number four is to "increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively."**

- The drive to improve work with family carers is reflected in the new **standards for inspecting learning disability services** published by the Social Services Inspectorate. At a strategic level services are being asked to demonstrate how "the role of carers is recognised by social services strategy and supported by appropriate investment."
- *'Valuing People'* seeks to promote a change in service culture that recognises that the relationship between family and professional is a crucial aspect of service effectiveness in delivering better services to men and women with learning disabilities. Developing partnerships with families is not an *optional extra* but a vital prerequisite in implementing. The *'Valuing People'* change agenda at a local level.
- Partnership Boards should not underestimate the challenge of building better relationships with families. the crucial question to ask is:

How do we create partnerships between families and services when relationships in the past have at times been more adversarial than collaborative?

Suggested levers for change include the following:

Families need to feel valued.	Staff need training to develop empathy with families, including training delivered by families.
Families need to feel listened to.	A range of different forums for constructive dialogue need to be created.
Families need to feel supported in their caring role.	Carers support services need to be developed and easily accessed.
Families need information.	Information to be provided in a range of formats – including accessing relevant training.
Families need to be financially remunerated for their contribution and to cover costs incurred in consultation.	Participation of family members needs to be budgetted for to cover expenses and training as well as caring costs.
Families receive independent support.	A dedicated worker to advocate for them – either as individuals or as group.
Hidden carers with high levels of unmet needs, need to be included in the partnership process.	Strategies to develop outreach projects need to be in place and liaison developed with voluntary, community and religious groups.
Families need to feel that their involvement in the partnership process is beneficial and constructive.	Regular feedback mechanisms need to be developed to feed back to family carers- using a range of accessible information formats.

Developing local services: older family carers

Why are they and their adult sons and daughters with learning disabilities a priority?

One simple answer would have to be – there are so many of them! People are living longer; both people with learning disabilities and their family carers.

- It is estimated that between 60% and 83% of people with learning disabilities live in the community, the majority of them supported by their families. The proportion of people being supported in the family home has not changed since 1969. (*Valuing People*, DoH. 2001.)
- A significant number of family carers (estimated about a third) are now over 70 and many of them are caring on their own. Significant numbers of people with learning disabilities are being supported by carers in their 70's, 80's and even 90's.
- Yet, many of these families are not known to services. Research in the UK, US and Australia suggests that up to 25% of people with learning disabilities are not known to the local learning disability services until their family care situation breaks down, due to the ill health or death of their main carer. (*Family Matters*, DoH. 2001)

- Significant numbers of middle aged men and women with learning disabilities will need to be supported when their parents can no longer care for them. With increasing longevity this post-parental care phase could be upward of twenty years for many men and women with a learning disability. Planning for this phase is essential. (*Moving On Without Parents*, Bigby C. 2000.)

Why single them out for special attention?

Although older carers share many characteristics with their younger counterparts, there are also important differences that have an impact on their need for services and support.

- **Growing older together:** they are continuing to care and getting older at the same time. Their needs as older people are often not recognised or catered for.
- **Isolation and limited support:** they are more likely to have reduced networks as spouse and friends die. They are more likely to be caring alone.
- **Mutual interdependence:** the relationship with their son or daughter is very important and this can develop into mutual dependency and very strong bonds. Many son and daughters take on an increasing number of caring roles for their parents. This is usually not recognised or supported.
- **Different experiences and expectations of services:** They have different experiences of services and the professionals in them than younger families. Their children were born at a time when there were limited opportunities for people with learning disabilities. Many families have had to battle for the most basic services for their sons and daughters, including education and day services.
- **Independent and going it alone:** They are less likely to ask for help just at the time that they might need more. Many families have had bad experiences with services in the past and have little or no confidence in what they have to offer.
- **Negative experiences of services:** These lifelong carers have often feel they have had a particularly bad deal from services. They feel judged and devalued by staff in services.

- **Facing discrimination:** Research has demonstrated that those people with learning disabilities known to services who live with older family carers experience discrimination. They are less likely to receive a service or have an individualised support plan, compared to other people with learning disabilities. (*Fair Shares For All*, Walker C. & Walker A. 1995.)

What older family carers say about the support they are looking for from services

Older family carers stress that it is important to them that the support they have given their son or daughter is recognised and valued by services and the staff that work in them. In the report, *'A Crisis Approaching'* (Magrill D. 1999.) the concerns of older family carers were documented. Six key points emerged as important for older family carers:

- **To be known** by services and have regular contact to both assist with the planning and enable assistance and support to be sought when necessary.
- **Provision of information** regarding local services for both short and long term.
- To ensure older people services and services for people with learning disabilities are **linked and co-ordinated**, and there is a central contact place for information and help.
- **A non-judgemental approach by workers** and awareness by them of the pressures experienced by parents and and appreciation of their expertise.
- Reassurance that **help will be available in a crisis**, that their dependent will be cared for and have support to deal with loss and bereavement.
- Involvement in planning, assessment, and decision-making processes regarding their son or daughter.

Developing good practice

- Despite a growing recognition of the key issues there has been limited development of practice wisdom here in the UK.
- Of the 16 Local Authorities contacted as part of the Lifetime of Caring project only 45 responded. Of these only a few areas had begun to develop a strategic or comprehensive approach to supporting this group. Many authorities had identified the issue as an area of concern, but had not yet developed a response.
- The seminal report *'Uncertain Futures'* (Walker C. & Walker A. 1998) urges local authorities to think strategically. Suggesting the local authorities need to give high priority to developing information systems that can help identify older family carers and create a useful database to assist service planning.
- They emphasise the fact that local authorities cannot rely on existing care management systems as so many of these families are not known to services and the triggers for assessment of need are not operating effectively.
- Mainstream carers initiatives cannot be relied on to provide the targeted support these families need. Research published by the Norah Fry Centre, *'In Their Own Right'* (Robinson V. & Williams C. 1999.), showed how poorly served family carers of people with learning disabilities are. The majority of families were not accessing their right to a statutory assessment under carers legislation. Those few that did experienced no discernible change in their support a year later.

Meeting the needs of families growing older together

Local Services, and in the light of the White Paper, local Partnership Boards, will need to develop service responses on three levels.

Creating a local context for good practice:

- Developing policies to support families growing older together (including links with elderly services and learning disability services).
- Appointing dedicated staff to target support.
- Investing in staff training.

Develop local outreach programmes:

- To help identify 'hidden' older carers.
- Facilitate peer support through group work.
- Target older carers for health provision campaigns.
- Develop family work which includes siblings in planning processes.

Develop support programmes that allow longer-term relationships to develop through continuity of contact:

- Visiting schemes.
- Flexible short breaks.
- Shared care schemes.
- Domiciliary and outreach support projects.

Developing local services: the challenge for local Learning Disability Partnership Boards

Meeting the needs of older family carers and their adults children with learning disabilities

What does the White Paper and the supporting guidance have to say in relation to improving support to families growing older together? A number of targets have been established and older family carers are an obvious priority. Local Learning Disability Partnership Boards will need to consider how they will deliver around the following objectives:

(Sub-objective 4.2)

- "Establish a complete picture of older carers (aged 70 and over) in the local area in order to plan services in partnership with them."
- Linked to this is "a proposed performance indicator of the percentage of carers of 70 and over for whom a plan has been agreed."

(Objective 6)

- "Enable people with learning disabilities and their families to have greater choice and control over where they live and how they live."

A local Housing Strategy to be developed by Winter 2002/2003

- "Developing 'supported living approaches' for people living with older carers will be a priority for both revenue and capital elements of the Development Fund."
- "Focus on developing short term breaks and identify older carers as a priority group for the Carers Special Grant 2001/2002."
- "Prioritise people with learning disabilities living with older carers for the development of the Health Action Plans."

Identification of health facilitators by Summer 2003

- "Developed person centred plans for people with learning disabilities living with older carers – significant inroads to be made by 2004."

How can local Partnership Boards start to deliver on these targets? Some simple questions that need to be asked:

1 How will you know what is needed?

Identification

One of the criticisms of the first round of Joint Investment Plans is the lack of connection between local needs analysis and local action planning. How will you know what is needed to support older family carers and their sons or daughters with learning disabilities, if you don't know who they are or where they are? A vital prerequisite for any service development has to be the development of a comprehensive database.

2 How will you make contact?

Proactive outreach

For Local Authorities without an up-to-date register this is not an easy task and will involve a range of approaches. Learning disability services will need to be proactive in establishing links with local...

- Older people's services,
- Primary care groups,
- Community and religious organisations,
- Voluntary organisations.

... to actively identify older family carers. This will require focussing attention outside learning disability services.

3. How will you ensure that the perspectives of older family carers are represented at Board level?

Dedicated workers

In areas which appear to lead the way in terms of services for older family carers, the role of a dedicated worker has proved critical. (See resources) Where the worker sits organisationally is less important than the fact that the role exists. In the UK dedicated workers for older family carers can be found employed in Local Authority – Social Services departments, a rural council, and voluntary organisations. They often advocate for individual families as well as raise the profile locally of this group and offer staff training and input into planning processes. They also help ensure that this group of carers is included in mainstream carers initiatives and provision.

What have you got to offer?

Many older family carers have had bad experiences of services in the past and this has affected their relationships in the present. If you manage to make contact – what have you got to offer that can overcome their scepticism and reassure them that future relationships will and can be different?

<p>Will services be delivered by staff that are empathetic and understanding, who are able to work in non-judgemental ways and really collaborate in partnership with older family carers?</p> <p>Will staff be skilled to work with them and have the knowledge to assess needs and offer support?</p>	<p>Staff training & Development</p>
<p>Will older family carers be able to access information about what services have on offer both now and in the future, how service processes work and important points of contact?</p>	<p>Information</p>
<p>Will older family carers be able to access training that might support them in their caring role if they should wish to?</p>	<p>Access training</p>

In what practical ways will older family carers be able to participate in person centred planning for their son or daughter?	Involvement in person centred plans
Will there be dedicated carers support staff and specialist support groups appointed locally?	Specialist staff
Will families be offered practical and emotional support? Will systems be in place which ensure older family carers have an ongoing contact with services at a tempo and pace that suits them?	Supportive services
Will local learning disability and elderly services develop joint protocols to ensure a seamless service to families growing older together?	Joint working
Will people have a real choice of flexible short-term breaks or will their needs for respite be slotted into pre-existing provision?	Short-term breaks
Will anyone with learning disabilities living with older family carers have an emergency or crisis plan that is easily accessible and regularly reviewed and updated?	Planning for the future
Will older family carers have access to Carers assessment and will having an assessment equate with getting the right sort of support?	Mainstream carers initiatives need to be inclusive

Developing local services: meeting the White Paper targets

The White Paper *'Valuing People'* offers a national framework and objectives for learning disability services. It is not prescriptive about how these things are achieved. Local Partnership Boards will be discussing these issues and thinking about the best way forward in their particular locality. Here are some ideas you might wish to incorporate in local discussions:

(Sub-objective 4.2)

- "Establish a complete picture of older carers (aged 70 and over) in the local area in order to plan services in partnership with them."

This objective is key to all subsequent efforts at service development for this group of family carers. If you don't know who people are, or where they are, it will be impossible to plan local services, with and for them.

Creating a database of older family carers, as recommended by Walker and Walker in *'Uncertain Futures'* is the prerequisite of any strategic approach.

There are two dimensions to identifying and engaging this group of family carers.

1. Improving contact and developing relationships with older family carers whose son or daughter currently uses a learning disability service. This can be improved by ensuring the named contact person has a clear brief in relationship to working with families. (See over) Services need to take a

proactive stance to engaging families through information, drop in surgeries, and support groups. Some local authorities are in the process of setting a clear standard for care management reviews, ensuring every person with learning disabilities over 50 has a comprehensive review, including the situation of their family carer.

2. Local services need to urgently develop proactive outreach programmes or projects, which reach beyond current learning disability services. Involving skills more typically associated with community development, such local support services need to reach out to:
 - Primary health care centres – engaging GP's and community nurses in the identification of families currently not known to the local learning disability services.
 - Community groups, religious organisations and minority ethnic and black cultural and political groups.
 - Information 'selling services' need to be disseminated to libraries, older people's services, supermarkets and post offices.
 - Greater use of the local media, TV, radio and newspapers to publicise what services have to offer the carer and the people with learning disabilities.
 - [Linked to this is "a proposed performance indicator of the percentage of carers of 70 and over for whom a plan has been agreed."](#)
 - ["Developed person centred plans for people with learning disabilities living with older carers – significant inroads to be made by 2004."](#)

All individuals with learning disabilities are entitled to their own, individualised and personal plan, irrespective of the planning tool used.

Discussed above are the five elements that this project recommends that need to be covered in a comprehensive, person centred plan.

It will be important to provide evidence that once identified services are able to offer concrete support (in whatever way is most appropriate) to the family carer and their adult offspring.

It is not clear what sort of 'plan' the White Paper means in respect to this proposed performance indicator. There is a range of potential plans that it might wish to see in place. These may include:

- Emergency or crisis plans,
- Plans for the future – to ensure a smooth transition from parental care,
- Current support plans.

A comprehensive person centred plan should incorporate a range of elements.

It is suggested that Local Partnership Boards should be working towards achieving the following standard in relation to person centred planning and people with learning disabilities living with older family carers.

1. All individuals with learning disabilities over 50 (or living with a carer aged 70 or over) should have a Lifebook, which records vital information about the person's past life, current situation and future aspirations.
2. All individuals with learning disabilities over 50 (or living with a carer aged 70 or over) should have an agreed 'emergency plan' – easily accessible in a time of crisis.
3. All individuals with learning disabilities over 50 (or living with a carer aged 70 or over) should have the opportunity to plan for the future. Families, including siblings, should be offered the opportunity to attend 'Future Options' workshops, which provide information on different aspects of planning for the future including:
 - Financial arrangements
 - Residential support options
 - Who will become the key person in the person's life once the parents are longer around or able? Who will advocate and look out for the person with a learning disability outside of the services?

Information booklets, videos and cassettes should be produced for families.

4. All individuals with learning disabilities over 50 (or living with a carer aged 70 or over) should have a current 'day-to-day' support plan, which always acknowledges the carer's situation and support needs. The carer's perspective should be formally recorded and regularly reviewed.
5. All individuals with learning disabilities over 50 (or living with a carer aged 70 or over) should have a Health Action Plan.

(Objective 6)

- "Enable people with learning disabilities and their families to have greater choice and control over where they live and how they live."

Local Learning Disability Partnership Boards need to ensure that people with learning disabilities have a range of residential and supported living opportunities. The percentage of people with learning disabilities living at home hasn't changed since 1969. The reality is that the majority of people with learning disabilities do not have any real choice where they live.

A Local Housing Strategy reflecting a spectrum of opportunity needs to be developed in relation to the local demographic profile and people's preferences established through consultation and individual assessment. Strategic links with local Supporting People initiatives need to be developed.

Learning Disability Partnership Boards need to get away from talking about 'beds' and start thinking about homes for people. Local choice should include:

- Residential homes,
- Supported living,
- Sheltered accommodation for older people with learning disabilities,
- Home ownership,
- Tenancies (in social housing and private accommodation),
- Family placements,
- Remaining in the family home.

Families, as well as people with learning disabilities, should be fully informed about the benefits and disadvantages of different options and how they are financed. Information should be disseminated through videos, cassettes, written information and workshops.

- "Developing 'supported living approaches' for people living with older carers will be a priority for both revenue and capital elements of the Development Fund."
- "Focus on developing short term breaks and identify older carers as a priority group for the Carers Special Grant 2001/2002."

'Respite care' has often been too narrowly conceived as a building-based service offering a break for carers from their caring role. Respite or short term breaks need to be seen in terms of offering a dual function:

1. A break for carers.
2. An opportunity for the person with learning disabilities to develop new experiences and/or relationships.

Local Learning Disability Partnership Boards need to develop a range of opportunities for older family carers and their learning disabled adult children.

These include:

- Breaks together – daytime trips or holiday breaks,
- Domiciliary support,
- Outreach community leisure opportunities for people with learning disabilities,
- Befriending schemes,
- Family placements,
- Residential – overnight – accommodation and support for the person with learning disabilities.

Currently, the percentage of people with learning disabilities receiving a short-term break is small. By extending the range of options local partnerships should be able to demonstrate a considerable increase in the numbers of people supported, as well as extending people's choices. Not everyone wants or needs an overnight stay as a form of respite!

- "Prioritise people with learning disabilities living with older carers for the development of the Health Action Plans."

Health Action Plans should form a distinct but integral part of the person centred plan. All people with learning disabilities aged 45/50 should have a health promotion and health maintenance assessment carried out by a Community Learning Disability

Nurse. Baseline assessment should also be offered to all people with Downs Syndrome at 30. The Health Plan should also include an assessment of the older carers health and both carer and the person with learning disabilities should be actively supported to access appropriate health care.

The Community Learning Disability Nurse should play a pivotal role in co-ordinating the health care needs of the people with learning disabilities and their family carer and linking them to both primary and specialist health care.

- "By July 2002 – establish a named contact for families, who will co-ordinate and monitor services, regardless of which agency provides them."

Establishing a named contact for families is a vital part of establishing a better approach to partnership working between services and families. This is the person who will be developing links with the family and building a relationship of trust. It will be crucial that the named person does not change frequently as continuity is a factor families say they greatly value.

The named person will be the bridge between services and families. They will:

- Liaise with the family carers and support them to participate by ensuring they are involved in planning processes and their perspectives recorded formally.
- Monitor the older carer's situation in relation to the family caring situation.
- Refer them for a carer's assessment, if appropriate.
- Liaise with the family in relation to the 'emergency plan'.
- Help co-ordinate the family contribution to the compilation of information of the person with learning disabilities – Lifebook.
- Ensure family carers are aware of and can access appropriate training or information sessions.

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