



LINK Response to Consultation on Wandsworth's Carers' Strategy

Introduction and background

LINK welcomes the opportunity to comment on the Wandsworth Strategy for Carers and Young Carers 2009-2014 and its accompanying Action Plan. LINK understands that this document was developed by Wandsworth Council in close consultation with carers through the multi-agency Carers' Strategy Group. Therefore, in line with the Government's new National Strategy which makes concern for carers 'everybody's business' – not just social services, the Strategy is jointly owned by Wandsworth Council, the Mental Health Trust and NHS Wandsworth and is supported by the Carers' Centre. It is proposed that implementation will similarly be rolled out jointly with full involvement of carers.

LINK was not involved at the developmental stage of the strategy but was invited to work in partnership on a consultation process to identify carers' priorities for implementation and we attended two consultation meetings held in August, one in Putney and one in Balham.

This response to the Strategy is based on the content of the Strategy and Action Plan documentation, the views expressed by 25 people who attended the two consultation meetings and anecdotal evidence from carers who have approached LINK. LINK's focus is on services for adults so comments are not offered here about services to children and young people.

Proposed Carers' and Young Carers' Strategy

There are estimated to be over 19,000 adult carers in Wandsworth; around 100 young carers aged 5-18 are currently supported by Wandsworth's young carers' project. The strategy recognizes that there are likely to be many `hidden` carers of all ages who are not currently known to services.

In 2008 the Government published a new National Strategy for Carers and Wandsworth's strategy sets out how national priorities are being worked on locally. It also sets out eight dimensions identified as critical by carers themselves which reflect the findings of previous surveys and research about carers' needs.

These are:

1. Information and advice...that gives you choice and control
2. Quality personalised care...that gives you peace of mind
3. Recognition and respect... treating you as a partner in care
4. Good communication...so you are listened to and involved
5. Quality breaks...so you can enjoy and achieve
6. Health and well being...so you can stay safe
7. Economic well being...the same life chances as others
8. Young carers...supporting your right to be a child

The Action Plan takes each dimension and identifies action to be taken to implement the strategic objectives. The Action Plan demonstrates a thorough painstaking approach that has involved listening to carers' views and trying to build on and develop existing good practice. Carers' views are brought to life with case studies and pertinent quotations. The plan identifies which agencies will be involved in each action and sets out which year the work will be undertaken. If this is achieved, it will enable carers to know what services they can expect and by when.

Carers' Response to Strategy

The following is a summary of the responses of the carers who attended consultation meetings in Balham and Putney. It is acknowledged that only a small number of carers attended these meetings but their comments reflect other comments made to LINK by carers, albeit anecdotally. The impression that LINK has gained is that somehow there is a gap between what is apparently available according to documents, policies and leaflets, and what carers actually experience.

Information

Carers felt that their information needs are now partially met and that Wandsworth Care Line and the Carers' Centre are helpful starting points but it would be useful to have a carer specific help line. Because needs are so individualised, people would value face to face contact with a person with whom they could discuss their situation. Concern was

also expressed about `hidden` carers and those who do not identify as carers who would not have heard of Careline or the Carers' Centre

Quality Care and Support

Carers had experienced barriers to accessing certain services for their service user, including parking facilities (very poor/expensive at hospitals) availability of personal care for complex needs or sheer complexity of negotiating systems. Good quality day care was seen as critical both for the user and the peace of mind of the carer. People caring for those with mental health issues feel that users should be offered a `home for life` rather than being expected to keep moving on. Flexibility and choice, for example with respect to which professional the user sees were also valued, when available.

Two carers reported that they had not been able to access a carers' assessment despite requests.

Quality Breaks

This has been a demand from carers for more than three decades but still seems to be unavailable. Emergency respite was specifically highlighted. Carers spoke about an excellent model offered by Crossroads which has now closed. Most carers are not in a position to pay for respite care and are requesting vouchers for free access to respite. Some carers were unsure about where to find information about access to breaks or respite.

Recognition and Respect

Carers suggested that some GPs don't recognise their role although they feel that the Council is working on the issue. Training courses are valued but it would be helpful if these could be certificated to further possible employment opportunities. Some carers cannot leave their service user and would welcome training in the home.

Misunderstandings about confidentiality still make it hard for some carers trying to access information on behalf of the person they care for or being given the information they need about diagnosis and treatment. Professionals need more training about this issue as attitudes are a key problem.

Good Communication

Carers still feel that they are not listened to even when they express their concerns to professionals. They feel they are not involved in decision making despite the outcome of the decision will have a huge affect on their lives as well as on the service user. They are often `the expert` on the person they care for. Carers of people living in care homes often find the staff there defensive.

Carers would like to be more involved in the recruitment and training of professionals to ensure a better understanding of the carers' perspective.

Carers feel that there has been a shortage of advocacy in the Borough and a request was made for improving recording standards by widening the use of audits.

Health and well being

Being able to attend to their own health and well being is dependent on having access to respite care. Resources for carers are not available at weekends and evenings when other family members may be able to offer respite. Carers were also looking for support to subsidise them to enjoy leisure activities such as cinema vouchers.

Facilities are rarely made available for carers to bring the person they care for to events. Taking users to hospital appointments can be stressful and choice of times for appointments would help. Carers should have a choice about whether or not they continue in their caring role, especially when they grow older, ill or frail themselves. (Research indicates very high rates of physical and psychological ill health among carers).

Economic well-being

Becoming a carer frequently leads to loss of earnings as it is so difficult to combine full time work with caring. Employers seem unaware of their responsibilities to support carers and carers are not always aware of their entitlements. Advice about entitlements, benefits and debt management would be helpful

Conclusion

The above picture that emerges from the small number of carers who attended the consultation events and is reinforced by carers' anecdotal discussions with LINK highlights the huge amount of work that will be required to implement Wandsworth's ambitious strategy. Most of the issues raised are covered within the strategy and have actions proposed to address them. It is the implementation that will be a challenge.

LINK recommendations for priority action

Ownership of the Strategy

The strategy is clearly a collaborative project across health and social care agencies. It would be further strengthened if ownership could be extended across all health and care commissioners and providers within the Borough.

Carer Participation

It is appreciated that this strategy was developed with the participation and involvement of carers looking after people from different user groups as well as young carers. Implementation will be strengthened with the development of specific good practice guidelines for involving an even wider range of carers, especially reaching those who need support with financial and practical problems of finding alternative care for their service user in order to participate.

From discussions about the consultation process, it emerged that Wandsworth does not currently have a data base of all carers who have received a carers' assessment not is there a way of identifying carers via records on service users. It seems that more work could be done to identify and communicate with carers who may be unaware of what is available, even before work is done to identify carers not currently involved with services.

Information

Establish and publicize a multi-lingual help line specifically dedicated to supporting carers with an option for carers to be referred for an individual discussion.

Quality personalized care

Adopt and implement a policy whereby carers are always consulted and listened to

- a) in the assessment and review of individual care
- b) where services are planned to be changed or closed

Recognition and Respect

Provide carer-led training and involvement in recruitment for relevant professionals to ensure that they fully understand the vital role played by carers as partners in care and their entitlement to be involved and to have a carers' assessment.

Good Communication

Establish a data base of carers in Wandsworth, inform them of their rights and entitlements and consult them about developments that may affect their lives.

Quality Breaks

Extend and publicize readily accessible affordable high quality respite care, including emergency respite and respite using the Crossroads model.

Health and well being

Extend and publicize counselling, support group and recreational services for carers, including provision at evenings and weekends taking into account the need of carers to find/pay for alternative care for their service user.

Economic well being

Ensure that the Carers' Help Line can provide relevant benefits advice, debt counseling and information about employment entitlements.

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