Dementia Care Partnership: More Than Bricks and Mortar

Prepared for the Housing Learning and Improvement Network by Sue Garwood

Key Partners:
Carers, service users, volunteers and the local community are DCP’s key partners, along with service commissioners: Newcastle Social Services, Newcastle PCT, and Northumberland Care Trust, North Tyneside Council.

Brief Description:
A registered charity and limited company, Dementia Care Partnership (DCP) has a number of features which make it distinctive – possibly unique – and well worth emulating. A complementary range of services for people with dementia and their carers enable individually tailored provision. An underpinning value base commands a high level of commitment from staff and volunteers. With an emphasis on independent living and individual fulfilment, people with dementia and their carers play a significant role, not only in determining their own support, but in shaping what DCP does. DCP has been awarded “Pathfinder status” by the Department of Health’s Social Enterprise Unit and will be going on to develop a series of social enterprises. This case study describes DCP’s services and approach.

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DEMENTIA CARE PARTNERSHIP CASE STUDY: MORE THAN BRICKS AND MORTAR

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INTRODUCTION

"DCP is one of the most creative organisations in Newcastle. Their commitment to providing a targeted service to each individual is second-to-none. They help people with mental health problems to fulfil their aspirations and do a good job acting as a pressure group for older people." Service Commissioner

Two things stand out to make the Dementia Care Partnership (DCP) distinctive and worthy of a case study:

- Values: The application of the “PEACH” philosophy which permeates every aspect of the organisation and its services
- Services: The diverse range of specialist services for people with dementia which complement each other to form a dynamic whole

This case study will give a brief description of the project. Links or references to other material will be noted at the end for those who would like more information.

BRIEF HISTORY

A registered charity and Limited Company, Dementia Care Partnership’s vision is “to be a market leader in offering replicable, specialist and alternative services in dementia/mental health care”, and their mission is to “deliver client-led services” which promote independent living, including:

- Specialist, flexible home support services
- Day opportunities including extended day services
- Independent supported living houses
- Residential short break services
- Carer support
- Education, evaluation and influencing practice

The seeds of DCP were sown in the late 1980s when a group of carers worked with the current Chief Executive, then a social worker, to identify unmet needs, attempt to address these and challenge the culture of disempowerment so prevalent within services. They started to provide a range of flexible, person-centred home support services for people with dementia who were considered to be at risk, but preferred to remain at home. In 1991, the West End Care Management pilot project was set up as a joint initiative between health and social services and funded by a Mental Illness Specific Grant of £60k. Its aim was to assess the feasibility of supporting people with dementia at home. As the project manager for the pilot, the Chief Executive brought the group of carers together as advisors. Their experiences led to the decision to set up a charity to address the unmet needs in a systematic way.

The Dementia Care Initiative (DCI) was launched in 1993 as a non-profit making charitable organisation, when the same carers became the board of trustees. Importantly, both the pilot and DCI were direct responses to listening to service users and carers who also played a significant part in shaping the services. The vision grew to develop alternatives to institutional care which would enable people with dementia to remain in their own homes for life, with support. In recognition of the fact that partnerships – between clients, carers, community groups and statutory services – have been crucial to the success of the initiative, the name DCI was changed to DCP in 2000. The Board of Trustees for DCP is made up of 14 members – 8 of these are current or former carers.

Services have continued to grow and develop, culminating in the opening of the Bradbury Centre in 2005, a multi-purpose inclusive resource which is very much part of
the Brunswick village community. 2007 saw DCP being selected as one of 25 DH Social Enterprise Pathfinders.

“PEACH” PHILOSOPHY

“I have always felt that their values are excellent and that they are good people to work with. Feedback from service users and care managers is very positive” Commissioner of day services

Many organisations espouse laudable principles, but not all of them manage to embed them so firmly and fundamentally as DCP appears to have done. Every step that is taken, or decision that is made, seems to have been measured against the “PEACH” principles.

P Person-led

“Person-led practice starts with the person, respects their rights to lead their lives as any other citizens and recognises their ability and potential to take the lead in all aspects of their life, thus preserving their identity.” All the services are tailored to individual needs and preferences.

“Person-centred” became “person-led” when a tenant in one of the independent living houses – a former baker – came up with the suggestion of forming a committee to raise money for outings by baking cakes and selling them. This proved a great success. While “person-centred” can imply a passive recipient, person-led is a more empowering notion.

E Empowerment

“Empowerment is about enabling people with dementia and their carers to retain control over their lives, recognising that in the process of empowering clients and carers, professionals must be prepared to be disempowered.” People with dementia are not seen as a ‘burden’ but as citizens who have a valuable contribution to make.

One of the reasons that DCI made a charge for services was to give service users and carers control over them. Service users are encouraged to retain and apply skills. For example, one lady who was a professional hairdresser was encouraged to do the hair of other tenants for a small charge.

Service users and their carers are supported to take responsibility where they want to, and DCP actively seeks opportunities which could promote service users’ participation and fulfilment.

A Attachment

“Attachment is a basic human need where a sense of security is gained through the presence of a trusted person or the familiarity of a place. Attachment can develop with a trusted person such as a support worker, or to a place such as a supported house, enabling a sensitive and gradual partnership of care and support”

This principle is applied in a myriad of different ways: recognising and supporting the individual’s attachment to their carer, family and friends, so providing support to enable these relationships to continue; matching staff to service users; introducing people to services gradually, building up familiarity and keeping the same staff involved from beginning to end if at all possible; if they have to move, keeping people with dementia in their own locality where feasible.
C  Continuity

Continuity is, in one sense, closely allied to attachment: “The continuity of care and support provided by a small team of support workers, from the same locality wherever possible, thus offering familiarity and security”.

In another sense, continuity with a person’s history, routines, interests and lifestyle is important to his or her health and well-being. Tenants in the independent living houses are encouraged to continue every-day activities such as answering the phone, opening the front door, making shopping lists and going shopping.

The care and support planning process goes into great detail about likes, dislikes, interests, lifestyles etc. Staff gather and record biographical information about the individual and use it in conversation and reminiscence.

H  Hope

To continue to live their lives as active, valued and participating members of their own community.

In some of DCP’s material, H also stands for “home for life”, an aspiration which provides the raison d’etre for the Dementia Care Partnership. While determination to enable people to live in their own homes for life does not succeed every case, it does in many, even where the individual’s dementia is in the most advanced stages. Emphasis on this aspiration helps to minimise the number of occasions when people do end up entering institutional care, motivating staff to do everything possible to avoid that outcome.

Training, Learning and Development

Training and staff development are fundamental to DCP’s PEACH philosophy. Every new member of staff undertakes a two-week induction programme covering core subjects which include Understanding Dementia and Protection of Vulnerable Adults with Dementia. In addition, incoming staff shadow other staff in their new place of work and are encouraged to obtain NVQs at all levels. DCP also provides specialist in-house workshops covering topics such as Communication, Loss and Bereavement, and Professional Boundaries. Carers and service users assist in the delivery of training. This training is supplemented by new additions or external courses to ensure staff are equipped to meet the needs of individual clients in the specialist areas of work in which DCP engages. DCP has “Investors in People” status.

SERVICES

In itemising the services and initiatives separately, it is important not to lose sight of the synergistic whole – how all elements gel, complementing one another, changing and evolving as a dynamic organism to meet the needs of unique individuals.

The primary goal of the services is to support people with a range of needs to remain independent in their own homes – those with dementia and their families, including younger people and those with moderate to severe dementia; those with other mental health problems and their families, including people from black and minority ethnic communities. The range and flexibility of services enable choice and tailoring to individual need.
Whilst delivering specialist services, DCP seeks to avoid segregating and excluding people from their families and communities; communities in which they have played a meaningful part. It has a very inclusive, integrating approach, and one intended to promote citizenship.

**Home Support Services**

DCP provides both a specialist and generalist home care and support service. Trained home support workers visit clients in their own homes for a minimum of 30 minutes up to a full 24 hour, seven-day-a-week service, providing both personal care and practical help. They also offer a befriending service, carefully matching staff member to client, to provide companionship and support. This may be to those living alone or to give carers some respite from caring duties.

The specialist service is targeted at those with dementia and other complex needs which cannot be met by more general services. Commissioned by the city council, PCT or privately (3500 hours per week), the specialist service will often be used for people who are self-neglecting and reluctant to accept help, who present behaviour problems or require palliative care. They are likely to be unwilling to consider residential care, or to have tried it but not settled. The service will start off with a short befriending and prompting visit each week, building up to a fuller, individually tailored care and support package as trust develops.

At the other end of the spectrum it provides intensive packages of care in very complex situations. For example, a gentleman who is a double amputee and also has dementia receives 57 hours a week. He needs to be moved using a hoist, and has a history of lashing out. The package comprises three double-up visits a day as well as three sessions of respite per week, enabling his wife to go out. Now that he has an electric wheelchair, he can go on outings too.

Using information from assessments and interviews with service users, relatives or friends, as appropriate, an information sheet is drawn up for support staff, who are then assembled, and each need and the best way of meeting it is discussed. For example, to prevent the above-mentioned gentleman from lashing out, staff know they have to explain calmly each action they plan to take just before doing it. This approach ensures that staff feel properly prepared for what they will be dealing with, and results in a better service to the client. If necessary they are also given specific training to meet an individual client’s needs; a good example is that of a 51 year old woman with an 11 year old son who has a learning disability. She is being discharged from hospital after a stroke, is unable to communicate, and needs 24-hour care. Before discharge staff met with therapists to learn the best way of helping her, and the co-ordinator met with her and a couple of friends to learn about her likes and dislikes.

Although the unit cost for the specialist service is only marginally higher than that of the generalist service, visits to people needing it are likely to be longer – and possibly more frequent. The consensus seems to be that it represents good value for money.

**HOME SUPPORT SERVICES**

- Generalist and specialist home care and support
- Specialist service for complex needs
- Round-the-clock
- Befriending to build up trust
- Careful information-gathering and staff preparation
- Individually tailored provision
Independent Living Houses

“I couldn’t wish for anything better for my wife. Staff are so dedicated. DCP is a very unique service. There should be more of them across the country” Carer

If a person’s home is not suitable, but he or she does not want to live in residential care, a referral may be made for one of the independent supported living houses. These are shared by a number of tenants, each with his or her own bedroom.

To be eligible, people need to have a confirmed diagnosis of dementia, be living alone and highly vulnerable, with the informal carer (if there is one) struggling to cope. Every attempt is made to re-house people within their own familiar locality to maintain networks and familiar routines.

DCP now has 14 properties scattered across Newcastle, providing 47 tenancies to people with dementia, other mental health problems or learning difficulties. The landlords are housing associations, while DCP provides the care and support.

The first was acquired in 1993 – a terraced house in Joan St – while the most recent, Dunnock Court, was built in 2006 using colour schemes and furniture chosen by service users. The latter comprises 5 two-bedroom bungalows whose design features reflect the lessons learned over the years. For example, two sitting rooms have been shown to be important, so that tenants are not thrown together all the time and separate activities can take place. Space for pacing, level access, bedrooms large enough to accommodate hoists, a garden, and visual access to minimise anxiety, are some of the other features incorporated into new-build developments.

All of the houses are “ordinary houses in ordinary streets” and appear to be welcomed, even protected, by the local community. Unlike Extra Care housing which tends to have more tenants in a given unit or scheme, the “independent supported living houses” are shared by two to four tenants only. This offers the advantage of intimacy and homeliness, but shared living would not suit everyone. For the most part, people are housed who would otherwise be in residential or nursing home care, and a very careful process of assessment, matching and familiarisation takes place before a person moves into a house.

Care and support is provided around the clock by a small team of support workers, generally to a ratio of 1 staff member to two tenants or 2:4 during the day, and 1 waking staff member per 4 or 5 tenants overnight. However care and support levels are adjusted according to people’s changing needs. Staffing is funded jointly by Social Services and Supporting People, although, due to funding cuts, the level of input has been reduced to 1:4 for a few hours during the day. Assitve technology is being deployed in Dunnock Court to allow for a slight reduction in staffing levels whilst ensuring that night staff are alerted immediately a tenant leaves the bed.

Some of the people housed are severely disabled, one lady for example being completely immobile and needing to be moved by a hoist. A number have been in the houses since their inception, and the level of dementia in many is quite advanced.

Care and support provision is person-led. Activities may be individual or joint. Houses sometimes join together for activities such as day trips and holidays, and carers are invited to join if they wish. Such activities are seen as very valuable; for one woman who felt her life was no longer worth living, a holiday in Blackpool proved a turning point. Meals may be individual or joint with some tenants helping to prepare them and others not, all depending on their level of interest and capacity. Daily living expenses are calculated on an individual basis.

Staff exude commitment to, and enthusiasm for, the PEACH philosophy, clearly doing their utmost to implement it, and the low level of staff turnover bears testimony to the level of satisfaction they seem to derive from their jobs. Families feel supported and tend to remain involved. Relatives at two separate houses during a visit were unstinting
in their praise for the service. Tenants themselves came across as well cared for, relaxed and happy.

According to the 2005/6 Annual Review, since the supported houses were established in 1993, 89 people have had tenancies. Of these 39 remain tenants, 32 had a home for life, and 18 moved to alternative accommodation. These were due to medical emergencies, behaviour problems affecting the tenancy rights of others, and in some cases, the unsuitability of the physical environment, in particular Joan St which has since been de-commissioned. In some cases where a home for life was provided, special health needs were met by DCP and local health staff working in close collaboration, for example, health staff training DCP staff to use a suction pump and monitor a drip.

“It’s absolutely brilliant. The staff know what they’re doing and are very reassuring. I wouldn’t wish my mother anywhere else. I would hate it if she were in a home.” Carer

**INDEPENDENT LIVING HOUSES**

- Shared living – own bedroom, shared facilities
- “Ordinary houses in ordinary streets”
- For people with mental health problems wishing to remain independent
- 2 to 4 tenants per house – 47 tenancies in total
- Round the clock on-site domiciliary care and support
- Person-led provision
- Daily living expenses individually calculated
- Staff dedicated to PEACH philosophy

**Day Opportunities**

DCP operates its day service in three venues seven days a week, with a total attendance of approximately 300 people per week. The service runs from 10 a.m. to 4 p.m., though the transport starts from 9 a.m. and finishes at 5 p.m. or later. In order to make the service more personal, staff will use their own cars to go and fetch some club members.

Day services are provided for people with dementia and other mental health problems. Referrals are usually for people with significant difficulties, whose needs cannot be met in more generic provision. The two provisions in Newcastle combine places block-contracted by Newcastle SSD with others spot purchased by North Tyneside and Northumberland, as well as privately purchased places. In Hexham, all 30 places for people with severe dementia come via a Community Mental Health Team assessment.

The day clubs provide relief to carers, promote friendship and companionship, and offer stimulating activities and support to participants. Attendees join activity clubs which interest them, and the focus is very much on individual preferences. Staff spend time with individuals as well as facilitating groups activities.

‘Pamper days’, manicures, hairdressing, makeovers, digital photography and computing are just some of the activities members enjoy. Drama, woodwork, golf, rambling, swimming, cooking, pool, singing and dancing are also on offer. The occasional indoor bowling tournament between the two centres is popular – and very competitive. Outings take place from time to time, including to the garden centre for seeds and bulbs for the gardening club.
Here too the staff dedication and commitment to the PEACH principles is apparent. A number of people who move into the independent living houses have grown to know staff through the day club and home support services, providing familiarity and continuity.

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<td>• Block and spot-purchased places – public and private</td>
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<td>• Carer relief</td>
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<tr>
<td>• Range of activities</td>
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<td>• Membership of activity clubs based on individual preferences</td>
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<td>• Emphasis on Individual development plans, not just care plans</td>
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**Carers**

DCP recognises that carers are the core, because if they are well supported, they manage to look after the person with dementia for a lot longer, making carer support a cost-effective measure.

Three carers’ support groups – also known as carers’ forums – take place at the Bradbury Centre with the aim of providing support and information for carers of people with dementia. They give carers the opportunity to share their experiences with others in a similar situation. Advice and information on specialist topics, such as legal issues are combined with support and activities designed to pamper and be fun. Whilst the format of the three groups is essentially the same, the membership of each differs slightly; one comprises partners who have been carers for a long time, is well established and takes referrals from outside DCP; another, newly established, caters for carers whose partners are in the early stages of using DCP services, mainly the day club; and the last, a more ad hoc group is specifically for sons and daughters of people with dementia.

Individual support is also provided through home visits, telephone calls and sessions at the centre. This service is available on an ad hoc basis to anyone who initiates contact with DCP, or whose relative is in receipt of other DCP services, but there is no help-line as such, as the resources are not yet available to provide this.

The carers’ activities are led by a paid part-time co-ordinator, herself an ex-carer and involved with DCP from the early days. She is assisted by an administrator and a volunteer who facilitates the most recent support group and does some of the one-to-one work.

There is recognition that the carers in Newcastle and environs benefiting from these services represent the tip of the iceberg. In 2005, a small group of deeply committed carers set up the Carers’ Development Group. They were concerned that despite the progress made, much remained to be done. The group has a direct link in to the Trustees of DCP, providing a more formal opportunity for influencing the strategic direction of the DCP. It also links in to the support groups, ensuring that shared issues identified in those forums become known and understood at a level where generalised action can be taken – locating an expert to enable carers to get the most out of the “system”, or informing service development. Its primary focus, however, is to achieve influence outside DCP. The group is keen, for example, to raise awareness and understanding of dementia amongst professionals in the health and social care sector – for instance, nurses on general hospital wards. Working alongside the Board of Trustees and the University of Northumbria, the group aims to raise funds to expand its work and evaluate its impact.
CARERS
• Three support groups
• Individual information, advice and support
• Carers development group to exert influence
• Inform local strategies

Residential Short Break Service
It was in 1995 that carers of younger people with dementia approached DCP to develop this urgently needed service for their relatives. The five bedded unit, fitted with telecare equipment such as door and bed sensors, was incorporated into the Bradbury Centre. The service was designed in the style of a hotel, with access to all the facilities and services within the Centre. Each room can accommodate both person with dementia and carer. Unfortunately, certain registration requirements have increased the cost of the service, obliging DCP not to take any new referrals until the future is clearer. There is, however, a lot of interest and DCP are hoping to get the service up and running again in the coming months.

RESIDENTIAL SHORT BREAKS
• Direct response to long expressed need
• Purpose built
• Hotel model

THE BRADBURY CENTRE AND PARTNERSHIPS
The design and facilities at the Bradbury Centre were influenced by clients, who advocated for a normal, non threatening environment with social, leisure and learning facilities in the heart of the community. The Chair of DCP (an architect by profession) and the Chief Executive ensured that lessons learnt over the years were incorporated. The centre was opened in November 2005 by the Duchess of Northumberland. The £2.1 million for developing the centre was raised through generous donations from a range of benefactors.

The local community of Brunswick made the Bradbury Centre very welcome, and DCP are encouraging its use as a meeting place for all. It boasts a range of facilities:
• a restaurant and coffee shop where it is quite usual to see families from the locality enjoying a cuppa, and in the process, starting to break down age barriers and the stigma of mental illness
• a gym whose use is gradually being built up
• a “playroom” which is hired out to any comers, including – for example – a breast-feeding clinic
• the day club activities room
• a hairdresser open to all
• a quiet lounge
• a “first aid” room where alternative practitioners such as aromatherapists and Indian Head masseurs provide their services on a voluntary basis to service users and staff alike
• the short break suite of bedrooms
The garden is being developed as a “community productive garden” involving clients, carers and the local Brunswick community. The Duchess of Northumberland kick-started the process by donating 21 fruit trees to create a small orchard.

Carers, service users, volunteers and the local community are DCP’s key partners, along with service commissioners: Newcastle Social Services, Newcastle PCT, and Northumberland Care Trust, North Tyneside Council.

DCP is working closely with a local school to develop a range of innovative projects in which both students and DCP service users participate in order to break down age barriers and raise awareness. These include placements for health and social care and a range of horticultural initiatives. There is also a close working relationship between the local church and DCP, with parishioners using the facilities at the centre, and the curator visiting people there and participating with others in a local community committee which discusses the development of the centre.

The nerve centre of the Dementia Care Partnership, the Bradbury Centre also provides offices and conference/training rooms for the organisation’s managers and staff. What is striking is the extent to which volunteers – some of them carers, others not – contribute to the vibrancy and development of the organisation. There are about 25 of them, and they undertake a wide range of tasks; staffing the reception, helping in the restaurant and coffee shop; assisting with day club activities; and providing alternative therapies.

In 2006, the “Bradbury Centre Cultivating Health and Well-Being Project” won the CSIP Positive Practice Award for specialist services.

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<td>Partnership with local colleges and intergenerational work</td>
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<td>Tackles stigma and discrimination</td>
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<td>Actively Involves volunteers</td>
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<td>Over half the Trustees are or have been carers</td>
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<td>DCP provides a voice for people with mental health problems</td>
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TO THE FUTURE…. SOCIAL ENTERPRISES

In addition to meeting some key challenges – reducing costs without reducing quality, or finding alternative funding sources – DCP is planning to develop its services into Social Enterprises to consolidate and formalise the ownership of service users, carers, volunteers and the wider community. It is one more step towards empowering people with dementia and their families, providing an opportunity to exercise citizenship. DCP is also keen to develop its services in such a way as to extricate itself from the vulnerability of dependence on local authority contracts.

The exact processes have yet to be decided, but current thinking is that there will be four interlinked enterprises. Asked why four, rather than one, the chief executive’s unhesitating answer was that it gives more people the chance to have greater control and a sense of ownership.

A volunteering and employment agency is likely to be the first social enterprise in order to aid recruitment of quality staff. But they need training, so a training social enterprise is likely to follow hot on the heels of the first one, working in partnership with Northumbria university. Home support is likely to come next and may well broaden the
range of support services offered. The fourth area to become a social enterprise will be
the day services, emphasising health and well being.

The Department of Health’s Social Enterprise Unit will be supporting and monitoring
progress, as well as evaluating DCP’s pathway into social enterprises. For more
information on Social Enterprise, see the Integrated Care Network’s latest report
“Integration for Social Enterprise” (details below).

CONCLUSION

The Dementia Care Partnership is an initiative which deserves the accolades it has
received. It offers an approach whose replication would be of great benefit to people
with dementia and their families elsewhere in the UK.

The range of services need not be identical. It is the diversity of complementary
services developed in response to the expressed needs of people with dementia and
their carers that should be emulated. And it is the total commitment of everyone
involved to the PEACH principles, both in developing and delivering the services, that
sets a standard.

The last word must go to Rani Svanberg, Chief Executive:

“With everyone on our side, enriching the lives of people with dementia and other
mental health problems within the heart of the community will certainly be achievable”

LEARNING POINTS

- Really listen to people with dementia and their carers
- Involve them in shaping, developing and controlling services
- Develop a diverse range of services that are flexible and responsive
- Tailor what you provide to the individual’s and carers’ needs and preferences
- Many people with multiple needs and advanced dementia can
  continue to live at home if the right, timely support is available to
  them and their carers
- Investing in training and careful preparation pays dividends
- Embed your ethos in everything you do
- Continually work with stakeholders to evolve and achieve your vision

LINKS AND REFERENCES

The following additional material can be found at the DCP website:

- 1998 Evaluation of the DCI pilot project to care for people with severe
dementia in their own homes
- 1998 Series of articles on the independent supported living approach
- 1999 Dementia North evaluation of an independent supported living house
  for people with early onset dementia
- 2005 – 2006 Annual Review
- 2007 DCP milestones

http://www.dementiacare.org.uk/index.html
“Integration for Social Enterprise”, Integrated Care Network, CSiP, Nov 2007 – a report outlining a range of social enterprise models which local authorities and NHS organisations can explore when seeking to integrate or work in partnership with local communities and the voluntary sector. Available at www.icn.csip.org.uk
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<td>Developing ECH in Cheshire: the PFI route</td>
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<td>Commissioning an ECH Scheme from Social Services’ Perspective - Leicester</td>
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<td>Broadacres Housing Association Older Persons Floating Support</td>
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<td>26</td>
<td>Unmet Housing-Related Support Needs in Wokingham District - an investigation</td>
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<td>Dee Park Active Retirement Club - Age Concern Berkshire</td>
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<td>Essex County Council Older Person’s Housing Strategy (Summary)</td>
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<td>29</td>
<td>Pennine Court: Remodelling sheltered housing to include Extra Care for people with learning difficulties</td>
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The Housing LIN welcomes contributions on a range of issues pertinent to Extra Care housing. If there is a subject that you feel should be addressed, please contact us.