



# 'All Together NOW'

Collectively figuring how to develop alternatives to just paid support

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## Background to the Paper

Four locally based, independent sector organisations that make up the D.E.L.I group organised a Thinking Day with John O'Brien in April 2009 to look at how we could 'continue to develop individually designed services at a time of reducing formal resources'. The day was excellent, but we felt there was a need to go deeper and to involve a broader range of perspectives.

We subsequently discussed how to do this with Carey Bamber of NWJIP, with Martin Routledge of Putting People First and with Helen Sanderson. We then invited a group of just over twenty people with a known interest in people having a range of support that goes beyond paid staff, to spend two days together.

Group members came from a range of settings which included the independent sector, family members, local authority, health and primary care trusts. The group met in November 2009 and again in February 2010 to discuss the ideas behind this paper. The differing perspectives group members offer were crucial, as we collectively face the harsh reality of reducing funding with increasing numbers of people requiring support.

The challenge was to find a way of figuring it out together, keeping to sound values and principles and coming up with some tangible ideas for moving forward. Simple, ill-thought out solutions will abound in the coming months and years; our aim is to prevent their implementation by coming up with appealing and well thought out options and alternatives.

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## CONTEXT AND LEARNING TO DATE

From the early days of normalisation, to the supported living movement, to the present move towards self directed support, the increasing importance of personal relationships and community participation has been recognised.

The present reality is that many services are based on the notion of all support being provided by teams of paid support staff. Many would agree that this reliance on paid support can often limit the creation of wider relationships and genuine community participation.

Some people would argue that our recent history is one of reasonably well funded services, which has led to:

- i. A tendency to over support people, and the creation of a model that has inadvertently built barriers rather than access roads to community life.
- ii. A lack of experimentation as it's kind of working. There are some fine examples of really innovative support, but so much provision is based on a model developed in the 1970's and 1980's. It's time to think outside the 'group home' box.
- iii. Levels of dissatisfaction not being high enough to generate change. We have a new government now that will surely assist this!

As the impact of the economic downturn and the dwindling public finances from the credit crunch hit public services in the UK, there is a growing pressure that all of us will experience of reducing funding over the coming years, and possibly longer.

There are two options. We can either wait for central, regional or local government to come up with solutions and be passive recipients of this. Or, we can be pro-active and take this opportunity to make a concerted push around developing alternatives to just paid support, promote better outcomes for people and be in control of our own destiny as funding reduces.

We do not want to be the victims of simplistic solutions which are mainly about saving money, many of which may advocate large scale services. We think the time is ripe to look for innovative and creative solutions, some of which we may have tried before. When the pressure is on, we think creativity and innovation often flourish. There are a number of questions this paper explores:

- What are people doing now or have done in the past in relation to informal, community or technology based support?
- What has worked which others can build upon?
- What hasn't worked, why not and how can we try it differently?
- What new ways are there for us to try?

The content of this paper has come from listening to and drawing out ideas from people's and organisation's stories and their efforts to explore what may work in today's world. Several of these stories appear in the appendices, and abridged versions of these stories will appear in the main text to highlight specific points.

We are particularly taken with the notion of just enough support, where people have neither too much nor too little (both of which can be equally bad), and where we work ethically and tirelessly to develop additional and alternative support through communities, families, technology and other solutions.

We see its relevance in all services, not just those for people with learning difficulties, though we are using our collective experience in this sector as our starting point.

### Purpose of this paper

This paper aims to share the thinking and practical ideas that have come from the two days. It's our contribution to the need to stop and think.

Many of the current models of providing services are neither sustainable financially, nor are they particularly desirable or successful in helping people to develop a wide network of family, friends and acquaintances, or to take on valued social roles. Hence the need to do things differently!

Our ultimate ambition is to create a dynamic, experimental culture within the North West and beyond. We hope it stimulates many serious attempts at reducing the reliance on paid formal support and at finding alternative ways of providing support that assists people to develop relationships and to connect with their communities.

### Why is this important?

- This is a joint issue for all stakeholders and it is important that we figure it out together; no-one group can do this alone
- It is important that we are proactive in being creative and imaginative to avoid the imposition of simplistic solutions which won't work
- With the current and foreseeable economic climate, it is important to make best use of all resources



- Over-support can be harmful to people's quality of life and often be a barrier to community participation
- With greater involvement of informal support arrangements, people can break from the restrictions that shift patterns of paid staff present
- The idea of just enough support should reduce intrusion into people's private lives of always having staff around and discourage the notion that people need constant 'surveillance' to be safe
- It will help us keep coherent with our values, beliefs and principles and a focus on the outcomes of personal relationships and community participation in difficult times

*"We can't be creative if we refuse to be confused.  
Change always starts with confusion;  
Cherished interpretations must dissolve to make way for  
the new." (Margaret Wheatley)*

## The challenge

The impact of the credit crunch in 2008 and the recession in 2009 has left the British government with a very significant level of debt. The intention to dramatically reduce public spending has been announced. At the point of publication we know that the Public Spending review, due in the autumn, will detail budget reductions of at least 25%.

However, this is only one part of a complex issue. The recent social care green paper, *Shaping the Future of Care Together*, estimated that the number of people over 85 years of age doubling in the next twenty years and an increase of 1.7M in the number of people needing care and support. All of this points to significant financial pressure over the next 20 years with Local authorities having much less to spend on each person and providers needing to find different ways to support people that are both less expensive and make better use of existing resources and opportunities in people's communities without having a significant cost implication.

## Key issue 1:

Finances are going to drive different ways of commissioning and providing support to people.

Ever since the first initiatives to support people with learning difficulties in the community, much has been spoken and written about the need to focus on supporting people to develop personal relationships. More recently, since the mid 1990's, and in particular with the focus on Supported Living, there have been intermittent efforts to try out different types of support (beyond the use of paid Support Workers), and to make a concerted effort to support people to build personal relationships. Whilst these initiatives have never been mainstream, providers, people and families have a broad range of experience of trying what would be seen as non-traditional support. The learning from this work over the last twenty years has been patchy, but it will become increasingly important in the future to build on these early initiatives and avoid re-inventing the wheel, as well as using every ounce of ingenuity and creativity to think of further ways to better support people, reduce costs and build more personal relationships.

## Key issue 2:

The focus on informal and community support has the potential to enable people to build more personal relationships and reduce costs at the same time.

Paid staff are both a necessity for many people and a potential barrier to true community inclusion. There is a danger that community members see no or little need to become involved in the lives of disabled people because 'staff are there to do that'. Using alternatives to paid staff, for many people as part of an overall package of support may provide opportunities for both more efficient use of resources and increased involvement from community members. Discovering the learning from the past (models of informal and community support have been around for over 30 years) and being inventive about alternative ways for providing support is a key challenge for commissioners and providers alike. Thus, building better and stronger relationships with people from outside of services has the potential for many positive outcomes. In *Crossing the River*, David Schwartz offered many examples of how an increase in community relationships led to greater safety and well-being.



## Steven

*Steven had been highly motivated all his life to have his own place, but his frustration with no one believing in him, resulted in behaviour that reinforced that negative view.*

*Finally given the opportunity, Steven quickly developed a lot of his own informal support with neighbours, and by being a regular and valued customer at a local club. Club staff tended to keep an eye out for Steven, who was friendly with a couple of other regulars who knew him though being support workers. One or two issues did arise early on, including the need for a change of clothes once. The club staff took care of this and 'loaned' Steven some clothes and subsequently asked for a set of Steven's clothes to be left behind the bar just in case.*

### Key learning;

- *Stand back and give members of the community the opportunity to demonstrate their resourcefulness and capacity to do the right thing.*
- *The employment of local people can speed up the process of being welcomed and included.*

## BUILDING ON EXPERIENCE, AND SEEKING ADDITIONAL AND DIFFERENT WAYS OF PROVIDING SUPPORT

If the above two challenges are to be met, services need to get much smarter at their creativity and learning. We must draw and build on the positive experiences and knowledge built up over the last thirty years whilst developing new approaches such as Individual Service Design and Support Planning to come up with modern creative ways of supporting people. This needs to involve different models of support, different ways to arrange for, pay and deliver services, the use of technology in new and more creative ways, and capturing every opportunity that communities present. The following section captures some of our best ideas and learning to date.

*"If you always do what you've always done  
you will always get what you've always gotten."*

*(Reinhold Niebuhr)*

### 1. Different Ways of People Receiving the Right Support

It is important that no one type of support is imposed on people. All organisations and families need encouragement and support to experiment with different support models. At the moment, there is a real lack of experimentation – much less than 15 years ago. There are three broad ways of moving towards people receiving the right support:

i. **Reconsider how much paid support people need.**

Often the original levels of support available have stayed in place, and are based on low expectations and a tendency to over protect. Are we too close to see how things could be different for someone? Have we taken time and developed a more person centred approach to re-thinking our concept of risk. Do we have a process in place to ensure a fresh pair of eyes has a look at the level of support?

ii. **Seek alternatives to formal paid support.**

What other support exists that might be preferable to paid formal support? How can the chances of making connections and wider relationships increase?

iii. **Create new or alternative models of support?**

Now is the time to try much of this. With the recession, rents are lower and there is a glut of property on the market with developers being open to suggestions. Individual budgets give more protection with shared support arrangements –



they can be a way to stop such ideas being glorified group homes where people have little control. Assistive technology is becoming mainstream, and there are lots of opportunities to always build this in from scratch when planning support. With the greater number of students, and people who are unemployed or have taken early retirement, there is a great big pool of people who may be interested in either shared living or community support. Experiment with the KeyRing concept, and develop a model aimed at people with higher support needs. There are some great examples of two or three people having individual flats within a block of flats and sharing the support and sleep-on support. Amongst some providers and commissioners, there is a real willingness to innovate; we need to capture this.

Some of the ways of replacing paid formal support include:

i. **Night-time assistive technology**

Support at night accounts for nearly 25% of expenditure in residential services. This equates to many hundreds of millions pounds per year – often for people who spend the night fast asleep. Too often, night-time support is provided 'just in case' there's a fire, a break in, the person gets up, there's a leaking pipe, the person wanders. Often this 'just in case' support is for reassurance, and an obvious area for support where technology can play a part.



## Roy and Dave

*Roy and Dave had shared the same tenancy for years despite being very different people. Individual flats would have been ideal, but there was no extra funding available.*

*A solution was found, at no additional cost, by finding two flats within a nearby block of flats. The use of simple assistive technology allowed the sharing of the sleep in and the same number of hours previously provided. Everybody wins in this situation, and the number of hours being provided are also now being reviewed.*

## Key Learning

- *Simple technology can provide the answer.*
- *Once you start reviewing the level of support that is provided, you're on a journey*

Already, ideas such as bed sensor pads, directional lighting, automatic toilet flushes, epilepsy sensors, motion detectors, and automatic links to monitoring stations and call centres are common place. Often such ideas are implemented more in services for older people and services for people with learning difficulties have been slow to take these ideas on.

## ii. Assistive Technology – An Enhancement to Practical Daytime Support

There are many examples of people making use of assistive technology to enhance independence, security and safety. Shared learning is often poor within an organisation, let alone between organisations. There is a need to coordinate what we collectively know and have learnt from what's being tried out:

- Many organisations have a lead person for assistive technology. We will pull together 6-8 such people to share their knowledge and to further develop this through visits to examples of excellent practice. (Contact Owen Cooper at [ocooper@iasservices.co.uk](mailto:ocooper@iasservices.co.uk) if you would be interested in this).
- There is hard information on what's available from Centres for Independent Living, some disabled people's organisations and from SMART houses

## iii. Support from a Good Neighbour

- An 'on call' form of payment for a neighbour to provide some reassurance type support, rather than fund an unnecessary sleep-on. Experiment with different ways of gaining very local community support.
- Look into reciprocal arrangements rather than payment e.g. dog walking in exchange for reassurance support.
- Customize such support, involving use of formal on-call support too.

## iv. Supplement support from the family and friends

- How do family and friends want to continue to be supportive? How does a provider avoid 'taking over' or giving the impression that they will be taking over?
- Encourage circles of support, so that family and friends make use of their Networks and direct how support is provided.

#### v. Using Individual Budgets to Drive Change

- People who assist with Support Planning can help people think widely, creatively and with a community focus.
- 'Criteria' for Support Planning with a focus on outcomes can encourage creative, community based solutions.
- Reviews seen as opportunities to exchange and explore creative, community opportunities.

## 2. Gaining the Trust of Families

We all work better together when we have the same information, even when that information is tough to deal with. Historically there has been a power imbalance between people working in services and families. This needs to change, and will change as people and families exercise choice and control through the implementation of the Personalisation Agenda. Our best advice is to:

- i. Recognise that the experience of the social care world for many families is negative, unsupportive and has been a struggle. It takes time to build trust and see that social care staff can be allies.
- ii. Facilitate support that starts with family's own connections and reciprocal relationships, and grow support through these relationships.
- iii. Share responsibility with families. Figure things out together, especially where formal resources are limited and there's a need to be creative. Make the time to understand each other.
- iv. View families as a resource in so many ways:
  - Staff Training
  - Interviewing
  - Development of the organisation – Working Together for Change; Family Forums
  - Support to new/other families
  - Beyond consultation to creative problem solving

- v. Highlight local stories where good quality, individually designed support has come about through the family being fully involved.
- vi. Create a continuum of choice and control. (See [www.iasservices.info](http://www.iasservices.info) and [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk) for one example of this ; and [www.paradigm-uk.org](http://www.paradigm-uk.org) for another example.) Provide examples of families taking on an Individual Budget with some technical support through to families using an Individual Budget to choose a provider and to direct the way support is provided. Provider being accountable to person and their family, and being replaced if not delivering what is wanted.
- vii. Find a way of providing guidance and support from people and families who have lived the social care experience. Find a way of gathering this knowledge locally and it being readily accessible e.g. impartial view on local providers, on professional advice e.g. solicitors etc.



## Jackie

*Jackie did not enjoy living in a group home and a move into a flat with one other person had a really positive effect. Soon many people believed a place of her own would be the best option, and work started on what it would take to make this happen. Specific concerns were identified, and one that Jackie's mum was particularly worried about was how Jackie had become de-sensitized to the fire alarm. Mum came up with a solution by finding a fire alarm which she could programme her own voice into. Jackie really responds to her mum, so hearing "Get out Jackie, there's a fire" in her mum's voice, works.*

*Jackie now receives six hours of support a day and has no sleep-ins. She is proud of her independence, of her home, and has very proud parents.*

### Key learning:

- *Fully involve the family in coming up with creative solutions.*
- *Less support might be needed in the right environment.*

### 3. Looking to Your Community

*“No problem can be solved from the same consciousness that created it. We must learn to see the world a new.” (Anon)*

Every community has capacity. The Asset Based approach to Community Development and other techniques have constantly shown that a capacity focus yields dividends. These have to be at the heart of support – it helps to build relationships, improve well being, and make best use of available funding. Any approach to change support and increase community participation has to be purposeful, intentional and made a priority. Some themes that emerged:

#### i. Common Interests

- Churches and other faith centres are conventional places to meet welcoming people, but are not the only ‘congregation of people’ in a neighbourhood.
- Find the passion and align with it. What's going on that a person can join with, add to etc.
- Can be local, but ‘community’ can also be further afield when it's about sharing a common interest e.g. singing in a community choir.
- “You'll never watch alone” scheme. See Appendix 2 for more detail
- Own allotment/garden; host a barbeque and invite other allotment holders. Model being a good neighbour and give neighbours any excess vegetables.
- Residents' Associations

#### *You'll never watch alone*



*“You'll never watch alone” is an initiative in Wigan which aims to connect fans with learning disabilities to fellow supporters to attend football and rugby matches, allowing people to engage with others and widen their social networks.*

*The scheme enables people to go to the match, not with a potentially disinterested support worker or family member, but with a friend, who is a like minded fan that shares their passion for the game.*

*The initiative has been so successful that it's expanding into going to concerts, the cinema and other entertainment.*

## ii. Find a Point of Connection

- A natural resource many people who are supported have is TIME. This can be a big asset. Look for ways of making use of this asset which benefit the immediate community (see one such example in appendix 3), and which create opportunities for connection, relationships, being valued, etc. e.g.
  - Holding keys for neighbours
  - Taking in parcels
  - Putting out, taking in bins
  - Involvement in neighbourhood watch
  - Visit lonely/isolated people; offer to do shopping, invite around for a coffee etc.
  - Time Banks/L.E.T.S.
- Be a good neighbour. Recent heavy snow re-ignited sense of helping each other. Call on a neighbour, everything ok? "Is there anything I can do?" etc. Going to the shops "can I get you anything?" etc.
- Look for opportunities, and take the initiative:
  - Someone moves into the street, welcome with a pot of tea
  - Gift to celebrate birth \*
  - Host a street party or similar e.g. Silver Jubilee, Fund-Raiser for current high profile emergency e.g. Haiti Disaster. Demonstrate concern for others and counter popular view of disabled people being recipients of charity.
  - Get involved in activity that helps the neighbourhood e.g. a clear up; Friends of Red Rec. etc.

\* 'Let's Use A Good Plate- Practical Wisdom in the Quest for Valued Social Roles'

John O'Brien September 2009.

### Jimmy

*"I moved into a block of flats where Joan, a friend of my mum lived. Joan came to my flat warming party and introduced me to several of my new neighbours.*

*My dad also suggested I pick up the litter on my road as many people around here are elderly and cannot do this, so I do this now and again. I also sometimes get things for an elderly neighbour when I go to the shops. She's told Joan that she's really pleased I've moved in next door, and its good to have some younger people around.*

### Key Learning

- Actively being a good neighbour pays dividends
- Family connections can open doors



### iii. Consciously Tap Into and Help Build Community

- Employ local people, with local knowledge and local connections. Advertise very locally.
- Free staff up to have dedicated time to make contact with people who are 'active', who are the connectors and the 'welcomers' in the neighbourhood.
- Create a post to initiate community connections and to co-ordinate all the small scale efforts.
- Phased withdrawal of support to give a person some unsupported time, and opportunity for connection without the 'guard'.
- Work with staff and develop their role in this. Focus down on the micro level i.e. street/neighbourhood; get to know neighbours and other local people. Develop ways of making connections and people becoming included.

### iv. Organisations having a Community Development Perspective

- Set up a fund that reinforces that the organisation is a resource in the communities it works in.
- Support very local neighbourhood initiatives both through active involvement and through financial support.
- Look for opportunities to fund small initiatives that improve a neighbourhood – host and fund a street party.

### v. Community Support from Community Facilities:

- Working with partners who might not traditionally see providing support as their role, and in the process, assisting them to become more equipped to welcome and support all members of the community e.g. leisure centres, swimming pools, libraries etc.
- Use a process like Working Together for Change to aggregate and analyse information coming out of Person Centred Reviews to identify what's currently not available and how people want to spend their personal budget.

### vi. Support from a Good Neighbour

- An 'on-call' type payment for a neighbour to provide some reassurance type support, rather than fund an unnecessary sleep-on.
- Customize such support, involving use of formal on-call support too
- Look into reciprocal arrangements rather than payment e.g. dog walking in exchange for reassurance support
- Ideally don't organise it; and let it happen naturally

The time is right to change support – all policy points to this. Community development is high up the agenda of government and all political parties. Lots of organisations are doing community mapping. This information needs to be either brought together or made easily accessible to all. Communities are rich in groups and people – accessing and engaging with them is the challenge. All families are members of communities, tapping into their resources and connections and working with them as real partners offers much potential. However, a change of attitude and approach from some professionals will be needed to make this work.

### Some further Ideas to Consider:

1. In Support planning, always consider paid support last, and focus on community involvement.
2. Providers to include in their mission that their role includes being part of community and promoting active community inclusion.
3. Commissioners to make engaging with and using community resources a strategic objective.
4. Investing in community resources (both providers and commissioners) to be a priority: time-banks, community campaigns and others
5. Recruit staff for their community experience and potential
6. Allow community groups to use your premises and resources and seek community locations wherever possible
7. Intentional communities involving local community members (not congregating large numbers of people with learning difficulties together)
8. Support which consciously and deliberately plans in the involvement of community members
9. Flat mates and Support Tenants



## 4) Working Together to Flourish

We are returning to a more mature perspective that recognises we might individually face different pressures and demands, and that whether our role is as commissioner, provider, individual, family member or ally, we can all sign up to a common vision. Supporting people to become valued and contributing members of their community, where they are surrounded by a network of family, friends and paid support is a purpose we can all work towards.

The benefits of co-operation and collaboration are clearly being felt, and only a few fantasists remain who believe that telling others what to do and then blaming them when the perfect world doesn't materialise is preferable to figuring out difficult stuff together. The next step in this process is for deemed competitors to look at how they might benefit from learning together and even working together. Smaller organisations could be at risk from larger organisations, and the economies of scale that they benefit from, unless they consider working with others and sharing resources.

The D.E.L.I. Group is one example in the North West where four provider organisations meet on a quarterly basis to share learning with each other, and to plan some joint training e.g. Leadership Training; Workshops with external consultants. A further step for the D.E.L.I. Group, and for similar networks, will be to consider the sharing of some 'back-office' functions e.g. HR, Business, and Finance.

Commissioners might reinvest savings that come from providers reducing costs through developing natural support by giving development grants to further develop this work. Building in incentives to achieve desired outcomes is likely to be more effective than merely clawing back any savings. We all need to recognise the difference between strategic commissioning to drive innovation and commissioning that just focuses on cost/competitiveness.

As previously mentioned within this paper, there is a real opportunity to pool our collective knowledge related to the use of assistive technology. We will pull together a representative from 6-8 different organisations to share and develop our expertise in this area.

## What have we learned already from experience about what works and what we need to do?

### People receiving support

- We need to create opportunities for people to demonstrate their capacity and resourcefulness.
- We all grow and develop when we receive the right level of support. Over protection can be as harmful as under support.
- Everyone involved in a person's life or with their support needs to see it as a core responsibility to raise people's expectations
- We need to be constantly looking for new and different ways to listen to people, especially people with different communication styles. Person Centred Planning has listening at its core. For Person Centeredness to become a reality, listening has to be at its heart
- When technology is used for support, often, the more simple it is the better – complicated solutions are not usually needed

### Families and Friends

- All professionals need to see families as true partners – not people on the periphery to involve when it looks good or feels convenient. For most people, their family will be the people who will always be there irrespective of funding.
- Shared values and understanding makes a big difference. This comes about the more people spend time together, learn together and socialise together. Joint training has been really helpful with this.
- Sharing people's stories raises expectations and gives people ideas. Peer support for families through programmes such as Partners in Policy Making and similar has been hugely beneficial.
- Talking about support and the lives people want leads to better outcomes than focusing on money.
- Asking families to think about their own resources (time, connections, interests, skills and money) pays dividends – worrying about offending people by asking gets in the way. This is particularly true for new families where there isn't an established pattern of a provider 'taking over'.
- We can start by truly seeing families as partners, sitting down together and building on existing relationships and connections.
- It is also crucial to identify, draw on and include other natural support that people may have through current friendships.

## Providers

- Strong leadership is essential, especially to guard against the pre-disposition for over-support.
- Thoughtful leadership is essential. Make the time to reflect on and articulate what you believe in and what you're trying to achieve. Involve all key people.
- Bold leadership is essential. Encourage innovation. Learn by doing. Celebrate good attempts. Become enthused by the sense of possibility.
- Develop a Person Centred Risk Approach – use well thought out tools to raise questions about how we have always supported a person.
- The role of providers changes the more non-traditional support is involved. Their coordinating and connecting role comes more to the fore.
- At reviews, people need to always look for ways to reduce 'over-support' and ask the question 'is there another way of doing this' – such a mindset produces different results
- Regularly check what over-night support does and achieves – ask whether the money will be better spent when people are awake
- From your knowledge of what and who is important to people, seek opportunities to build alliances – providers are only one part of the support equation
- Supporting PAs both has a positive impact for all disabled people and enables providers to learn about a different support relationship
- Recruiting (local) people with connections and concentrating on their people skills, rather than just experience pays dividends – ask at interview "Tell us how you're involved locally?"
- Invest time for staff to reflect on and understand their role in assisting people to make connections and become valued members of their communities.
- Think beyond 'people' as the only resource. Consider technology and other supports e.g. support dogs.



## Terry

*Terry had spent many years in the medium secure unit and his reputation ensured there was sufficient funding to establish an individually designed 24/7 service. This level of support continued because things were going well and the support enabled interesting things to happen e.g. the setting up of Terry's small scale horticultural business. The 'Thinking Day with John O'Brien' made us question whether we'd been over supporting Terry. We used the 'Person Centred Approach to Risk' booklet as a way of engaging with Terry on this issue, and as a way of re-looking at the support we provided and why.*

*Time without support was gradually introduced and Terry now has three hours a day without support. Terry's delight with this is obvious, and it's matched by staff's enthusiasm for and pride in Terry's success.*

*N.B Sleep ins are being phased out as we go to print*

### Key Learning;

- *Having a tool that supports and structures the process;*
- *Frequent reviews to monitor progress and to ensure it's going at the person's pace.*

## Commissioners

- Focusing on outcomes rather than outputs leads to better decisions and better use of money
- Commissioning needs to be about developing a helpful infrastructure to enable people to lead their lives and to get the support they want. Ideas such as peer support should be at the core of any commissioning strategy
- When risk is embraced (i.e. identified and a positive problem solving approach taken to 'how can we make this happen'), people get better lives.
- Outcome focused reviews of services should influence purchasing and commissioning decisions. A systematic way of collecting and aggregating person centred planning information should be used, which will then inform decisions. E.g. The Working Together for Change Approach.
- Constantly challenge your perceptions of power and ownership – just because support is funded, commissioners do not have a divine right to have a say in how people lead their lives.
- Do more things together with providers and families – breaking down the barriers leads to better working and a better shared understanding
- Provide incentives to be honest about money – a culture of clawing back all unspent money does not work. Promote and develop the practice you want to see by converting savings into development grants.

## Top Tips

1. Look to opportunities for people to contribute through valued social roles and through taking on responsibility.
2. Create opportunities for people to demonstrate their capacity and resourcefulness.
3. Develop the concept of 'Just enough' support. The concept of 'just enough' support aims to provide the optimum level of support which will increase the chances of people making connections with other people in their communities. Over support is potentially as harmful as under support, in creating unintended barriers.
4. Reduce the reliance on paid formal support, and create opportunities for alternatives to emerge, many of which assist people to be more actively included in their communities. Involve families and get to know and trust community members.
5. From the outset, explore how paid staff can supplement support from the family and friends. Avoid giving the impression that the provider will be taking over.
6. Asking families to think about their own resources pays dividends. Worrying about offending people by asking, gets in the way.
7. All professionals need to see families as true partners – not people on the periphery to involve when it looks good or feels convenient.
8. Recognise we are sometimes too close to see the problem of over support or over-reliance on paid support. Develop a process for reviewing how support is provided.
9. Take the initiative to avoid the imposition of ill-thought out, simplistic solutions.
10. Employ local people, with local knowledge and local connections.
11. Don't let 'we've tried that before' limit your thinking. Experience and knowledge built up over the last thirty years needs to be rekindled, tried out again and built upon.
12. Be honest about how things are, and about the gap between where things are and where we want to be - this is a collective issue for all stakeholders and it's important we figure it out together.
13. Over- support can lead to community members seeing little or no need to become involved in the lives of disabled people because "staff are there to do that".
14. Thoughtful leadership is essential. Make the time to reflect on , and articulate, what you believe in and what you're trying to achieve.
15. Celebrate! We need to create an experimental culture that learns by doing, and celebrates good attempts as well as successful ones.
16. Be bold. Believe that you can make a difference!

## Questions to Reflect on with Others

1. When we have reduced support to people, what have we seen? What have we learnt from doing this?
2. How could support be provided in a way that doesn't rely so heavily on formal paid support? In what other ways could this need be met? List out five ways where informal support could be provided?
3. Think of five ways a person you know or support could do things for a neighbour, and which might result in a reciprocal favour?
4. We broadly know what we could be doing. What is stopping us acting on ideas that we sign up to? What is preventing dynamic implementation?
5. What are we doing in our area or authority to pull people together to explore possibilities / alternative ways of providing support to how we always have?

## Final Thoughts

We hope this paper has demonstrated that there is a need, regardless of funding pressures, to seriously reflect on how services are commissioned and provided. The reducing funding might have woken us up to the need to do things differently, yet that need already existed. Our attempts to develop alternatives to just paid support and to assist people to become valued and contributing members of their communities have lacked urgency. That has just arrived.

The paper has been written as both a 'think piece' to encourage better thinking and ideas, and partly as a guide to steer providers and commissioners to achieve better outcomes for people at a time of diminishing financial resources.

If you were looking for ready solutions, you are probably disappointed and are likely to have stopped reading before now! If you were looking for ideas to kick start some new activity, then hopefully you've found something of use. Some of our Top Tips are listed on the previous page.

It calls for strong leadership. Leadership that can make sense of the current reality, that pulls people together to figure things out and that inspires people with the sense of possibility.

*"SOMEBODY HAS TO DO SOMETHING  
AND IT'S JUST INCREDIBLY PATHETIC  
IT HAS TO BE US"  
(Gerry Garcia)*

## APPENDIX 1

### Describe the story in one paragraph

Steven had a 30+ year history of moving from one residential place to another; seeming lack of insight that his behaviour might be related to living in environments he found intolerable.

When Steven was referred to us, it was soon clear that he was hugely motivated to move into his own place. We/he eventually found the ideal environment for Steven – a one person bungalow in an elderly person's development.

Steven is quite skilled at making connections/ friendships, and he soon questioned the level of support we were providing. Support was more than halved to 30 hours / week after 4 weeks.

Steven became a regular at a local Working Men's Club, which was also used by one or two local staff, who knew Steven. Club staff tended to keep an eye out for Steven, and one or two issues did arise, including the need for a change of clothes. Staff at club sorted it out and subsequently asked for a set of Steven's clothes to be left behind the bar.

### In terms of informal/community/ technology support, what was the contribution to the person's support

Steven developed a lot of his own informal / community support by being a regular at the club and by being a valued customer.

He's friendly and made a good cup of tea.

Used careline and home phone programmed for our on call too.

### How did you go about getting/ developing the informal/community support

We found the right environment. Steven did the rest.

Employment of local staff with good local connections.

### Describe the paid support in the arrangement; how did it change with informal support

Quickly reduced as Steven demonstrated his capacity and resourcefulness and he questioned why we were providing the support we were.

He wouldn't want staff around when he was with neighbours and would send them away if they arrived when he was with a neighbour

### Outline the costs of the support

Short term increase in costs when Steven first moved out of the shared tenancy. This reduced within four weeks such that group home no longer had a 'vacancy' as previous costs for four now even less as a 3 +1. Savings reinvested into development opportunity for another person.

(continued)

What is your key learning in terms of things worth doing again

Employment of local people has a knock on effect for being welcomed and included.

Give members of the community the opportunity to demonstrate their resourcefulness and capacity to do the right thing.

Invest time in finding the right environment .

What is your key learning in terms of things to avoid doing

Don't underestimate a person's capacity. We all have the tendency to over protect. Providing support because we do without being absolutely clear what it's for and why it's needed.

Believing you know how to do it. Continual learning and need for regular reflection.



## Describe the story in one paragraph

Jackie is a woman who has used services for many years while living at home with Mum and Dad, over the years she had developed a "severe reputation", so much so that she was known to adult's services long before she was of an age to access them.

Jackie adored her Mum and was always central to family life, however, this often lead to Jackie wanting Mum's sole attention and demonstrating this in ways that became increasingly hard for the family to manage. It was finally agreed that Jackie should move out of the family home into supported accommodation. The traditional "matching" exercise took place and Jackie was placed with a provider who happened to have a vacancy!

Although this helped the family situation, it was clear from the outset that the group setting did not suit Jackie in the slightest and she expressed this the only way she knew how. Rather than achieving her potential, the setting only succeeded in increasing the severity of her reputation.

The situation unfortunately continued for a couple of years before Jackie moved into a 2 bedroom flat and shared with one other person. Jackie and her flatmate had an average of 10 hours of support per day between them, and shared a sleep on and access to 24 hour support with an adjoining flat.

Jackie thrived in this new environment, learning new skills and enjoying her own space. The team quickly worked out that Jackie need much less support than they had previously thought and began to explore what it would take for her to have unsupported time.

## Several risks to this were identified;

Jackie had gotten used to the fire alarm being tested on a weekly basis , this meant that Mum and the team had real concerns that she wouldn't leave the flat if there was a fire unless she was prompted to.

Jackie loves a cuppa, but her hand shakes badly when lifting the kettle. The team had tried a kettle tipper, but without success. If Jackie was in alone there wouldn't be anyone in to help make a cup of tea and she might scald herself picking up the kettle. This would be likely to happen as Jackie likes a cup of tea whenever she feels like one and would not wait long for support.

(continued)

Jackie's mum and the team put their heads together and did some problem solving. The team knew that they had contributed to de-sensitising Jackie to the fire alarm and made an agreement with her to only test the alarm when she was out of the flat. Mum found a fire alarm which she could programme her own voice into. When the fire alarm sounds, Jackie hears the voice of her Mum telling her "GET OUT! GET OUT JACKIE, THERE'S A FIRE!" Mum also went to Argos and bought Jackie a 10 second kettle, this doesn't need lifting as the cup is placed under the spout. Jackie learned how to make herself and her guests a cuppa really quickly. Initially Jackie had a couple of hours to herself per week, then per day.

Since then Jackie has moved out of the shared flat and lives in her own house, she has gone from the experience of 24 hour support to having 49 hours per week. Incidents of harming herself or others have dramatically reduced, not because she been on anger management training, but because the environment is right. She is proud of her independence and of her home.

<p>In terms of informal/community/technology support, what was the contribution to the person's support</p> <p>10 second kettle</p> <p>Personally recorded fire alarm</p>	<p>How did you go about getting/developing the informal/community support</p>
<p>Describe the paid support in the arrangement; how did it change with informal support</p>	<p>Outline the costs of the support</p>
<p>What is your key learning in terms of things worth doing again?</p> <p>Involving family in the problem solving as this alleviated what could have been a block</p>	<p>What is your key learning in terms of things to avoid doing?</p>

## APPENDIX 2

### Never Watch Alone

Is an Initiative which aims to connect fans with learning disabilities to fellow supporters in order for them to attend football and rugby matches, allowing them to engage with others and widen their social networks. The Never Watch Alone Initiative (NWA) has been developed through consultation with self advocates who have learning disabilities and who are connected to the Big Chat, Advocacy Steering Groups etc. This is a unique partnership between the DW connecting team, NADS (National Association of Disabled Supporters) and Wigan Learning Disability Partnership Board.

The NWA is very proud to have the highly respected Ex-Wigan Warriors player and current Sky Sports Presenter, Phil Clark, as it's Ambassador. Phil helps to promote Never Watch Alone both locally, and, using his regular TV appearances, nationally.

Once Buddies have been connected, the aim is to enable people to lead a full, purposeful life within their local community, helping them to develop a wider range of friendships, relationships and opportunities. Through the network of Buddies, the NWA enables those supporters with learning disabilities to go to the match, not with support workers or care givers, but with a friend, who is a like minded fan that shares their passion for the game.

The Initiative is coordinated by a user led organisation called Embrace Wigan and Leigh, who have successfully matched 52 Buddies to date. The Initiative is fast becoming known nationally and the following quote was given by Alun Francis, Disability Liaison Officer at Arsenal FC, following NAD's recent AGM:-

“Just to say congratulations on a great AGM today. I thought all the presentations were really good, particularly the Embrace Never Watch Alone Initiative, which I will definitely look at replicating here at Arsenal”.

Person centered matching tools are used when buddying-up people. This has proved to be a real success, connecting people from all backgrounds and allowing them to experience life changing events in an enjoyable, meaningful way, also encouraging some very positive relationships to form.

Michelle Ryan (Embrace Wigan and Leigh) who coordinates the Initiative, feels that Never Watch Alone, which is celebrated locally, is a fantastic model and something that could and should be replicated nationally.

### Michelle Ryan

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## APPENDIX 3

### Good neighbours make good friends

My name is Jimmy and I grew up in Salford. My loves are my family, my job, Manchester United and fashionable clothes. I know Salford very well as I have always lived here apart from 3 years when I lived at college in Wales.

I have always wanted my own flat and a girlfriend. Some people thought I never would get these as I sometimes get into trouble but I knew I would.

I got my first flat 7 years ago and at first it worked very well but then new neighbours moved in and they made things very difficult for me. They were alcoholics and very nasty to me. I had had problems with the previous neighbour and the housing officer helped me sort this out by going to court, but this was worse. It ended up with me being very frightened and I began to do some silly things. The final straw was when the neighbour threatened me with a knife.

Then I needed to move and my family asked me to move back home while I got a new place. Lots of people helped me get a new flat by writing or ringing the council. I was very lucky as it did not take long.

I now live near my Mum and Dad in a brilliant 3 bedroom flat. I have a bedroom, a guest and a laundry room!

Now I am busy getting to know my neighbours. I am lucky because a friend of my Mum's (Joan) lives in the same block. They used to work together and we have known each other since I was little. She came to my house warming party and has introduced me to other people who live near me. My Dad has suggested I pick up the litter on my road as many people are elderly and cannot do this so I am doing that now and again. There is lots of litter at the moment as the builders are doing work on our flats. I get on really well with them as they are my age and we can have a laugh. The other great thing about the building work was that the council had a meeting about it and because I went I got a raffle ticket and won the top prize of a 32 inch television. Lucky again!

The lady who lives next to me is old and cannot get out much so I sometimes offer to do her shopping if I am going to the local shops. She asks me to get her milk. She has told Joan that she is really pleased I have moved in next door and it's good to have some younger people around.

Besides making new friends I have kept in touch with my old mates. Darren is my best pal and he has already used my guest room lots. He stays over when we have had a late night watching sport on television. At the moment he lives in adult placement, but I think he's begun to think he would like a flat like mine.

Next week I have invited an old friend round for tea. She lives in the group home where I used to live and we have kept in touch although I moved out seven years ago. She will not be able to get up the stairs to my flat but I am going to make a picnic to share in the communal garden, and if it rains we'll go to the local pub. In fact we may do that as well even if it's sunny.

It's easy to get the bus to my job and I don't plan to job hunt as I'm happy there and know everyone and what to do after seven years.

I am still getting to know my neighbours but my support team are amazed how many people I know around here. I tell them it's because I grew up here.

I feel much better and think it will be much easier to stay out of trouble now. I had some really good help from the Calderstone's forensic team and I know I can manage my temper by following the things they taught me. My old and new friends are really important to me and I will keep them.

## PARTICIPANTS

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Carey Bamber

Chris Barker

Irene Byrne-Watts

Dave Clemmett

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Brenda Copnall

Lynne Hamnett

Gemma Homan

Kim Howard

Lyn James-Jenkinson

Peter Kinsella - Facilitator Day 1

Bev Maybury

Tony Pounder

Martin Routledge

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Isabel Southern

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Jan Swan

Caroline Tomlinson

Sally Warren – Facilitator Day 2

David Whyte

Alan Williams

Richard Williams

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