



Good practice in involving families in your workforce development: **the what, why and how**

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Forewords



When I joined the Care Quality Commission (CQC) as chair in October 2010, I said how important it was for us to capture people's views and experiences to help inform our judgements. At the CQC we are constantly seeking to drive forward improvements to ensure that there are safe, quality services across the country. This timely report highlights the important role that families can have as valued partners in developing and supporting those improvements. The organisations highlighted in the report have identified the key support that families can give them in meeting the challenges ahead and making judgements about what really matters. At the CQC, we hope that other providers will consider how these approaches could support their own drive to deliver safe, quality services.

There may be times when there is conflict between family members, it is a feature at times in all our lives. Family members are often however, the 'experts' in understanding the needs, hopes and aspirations of the person with a learning disability. It is likely that they will have been the consistent and constant thread running through the person's life. In my work at Mencap and at the CQC I have been inspired by the commitment and dedication of family members.

This document talks of partnership. For me that means that professionals must respect the role of the family and, in particular, listen to their point of view.

Dame Jo Williams, chair of the Care Quality Commission



Family carers of people with a learning disability are a hidden workforce. They have incredible reserves of commitment, passion, knowledge and expertise. They are often the experts in the care of their son, daughter or sibling, and have knowledge of their journey through life – the history that informs their identity and shapes their future. Offering good support to people with a learning disability means offering good support to the people closest to them. Families matter.

Carers with a learning disability are a small but significant group. It is important that their needs and experiences are heard. They can really help organisations working with people with a learning disability to think about the support that is needed. Birmingham University has involved carers with a learning disability in their training for social work students. It's a great example, but we need this to happen more and more.

This report highlights examples of a range of providers who have understood the real value of involving families more fully in their work, giving family carers a voice and role, and fostering a new culture and relationship built on mutual respect and trust. In these challenging times, the organisations highlighted have taken a strategic long-term view of this investment, believing that the involvement of families is key. We hope that other providers reading this report will consider how they involve family carers in workforce development and think of the long-term benefits to be gained by pursuing the kind of approaches highlighted in this work.

**Anne Williams CBE, national director for learning disabilities and
Scott Watkin, co-national director for learning disabilities**



Family carers have been at the heart of Mencap since we began in 1946. As an organisation we are committed to putting people with a learning disability and their families at the centre of everything we do. We know that families are often the experts and have skills, knowledge and experiences that are invaluable. It is important that we recognise this in the truest sense, by ensuring the families are involved in all key aspects of our work; including workforce development.

This project, funded by the Department of Health, highlights the good practice of a number of different agencies and organisations across the country who are involving families. We have talked to families who have told us what they think would be good practice and how they would feel valued. We have also brought together the good practice sites to share their top tips in involving families.

At Mencap we know that we have made huge progress in involving people with a learning disability in workforce development. We now need to ensure that families are at the heart of that work too. We will be taking forward what we have learnt from this report to look at how we involve families in our workforce development, as well as encouraging others to do the same. Families are an equal and invaluable partner. Our workforces – and families’ confidence in them – can be all the stronger when we work together.

Mark Goldring, Mencap chief executive

Contents

- Introduction** **6**

- Workforce development – why you should involve family carers** **7**

- Workforce development – what families can bring** **9**

- Involving family carers – making it happen** **11**

- Developing your partnership with family carers** **12**

- How involving family carers can help providers achieve Care Quality Commission outcomes** **14**

- Families developing the workforce – good practice examples** **21**
 - Supporting Rebecca **21**

 - Families and self-advocates working together **23**

 - A family-focused organisation **25**

 - Partnership working in the eastern region **27**

 - Families as trainers **29**

 - Involving family carers who have a learning disability in social work training **35**

 - Family input into management teams **40**

- Conclusion** **43**

- Acknowledgements** **45**
 - The authors **46**

- References and resources** **47**

Introduction

The government white paper, *Valuing People Now*, says that people with a learning disability and family carers are not always involved in training workers or making plans about the workforce. In 2009 the *Valuing People Now* team commissioned some research. It showed that there had been some progress towards involving people with a learning disability in workforce development. However, it was hard to find examples of families being involved. When we talk about family carers in this report, we are talking about people, almost always family members, who voluntarily give someone a significant amount of support that they could not manage without.

This report is intended to encourage and assist the involvement of family carers in developing the workforce. We hope that any organisation whose workers come into contact with people with a learning disability will find it useful.

Since the publication of *Valuing People* in 2001, people with a learning disability have moved out of hospitals and into ordinary houses, started to find interesting activities in the community and some have found jobs. They use a wide range of services such as buses and trains, leisure facilities, shops, banks, post offices, libraries, cafés and pubs, to name but a few. This means that any organisation providing a service will have people with a learning disability as customers. These organisations might like to consider how family carers could help them to offer a better service to people with a learning disability. It might also help them to think about other groups of people who may use their services, because getting it right for people with a learning disability means making it better for a lot of other people too. However, it is organisations that provide specific services for people with a learning disability who will find the report most useful.

Working closely with family carers themselves, we have looked at why it is a good idea to involve them in developing the workforce, what good practice looks like and what families can bring to workforce development. As well as offering some useful examples that show how families are already contributing, we have suggested some ways that this kind of family involvement could help providers to achieve the outcomes required by the Care Quality Commission.

Workforce development – why you should involve family carers

Community empowerment is a key part of the coalition government's concept of a 'big society' where local people and communities work together towards a stronger future. Family carers are part of the community who use social care and health services. Using their knowledge and expertise to develop workers is a good way to empower them. There are some important policies and organisations that already recognise what they have to offer.

“ Carers represent an essential and largely unrecognised part of the social care workforce. There are over 6 million unpaid carers in the UK. They provide assistance that cannot be offered by commissioned services and can, in some instances, communicate the needs and wishes of the people they care for. They can offer a valuable insight into working with people who use services and the gaps in the social care system.”

Strategy for the Participation of Carers in Skills for Care Work, November 2007

“ A range of reasons was given by Higher Education Institutions for the involvement of carers; the predominant reasons included recognition of the value to practice of learning from direct engagement with carer experience and valuing an approach which reflected the inclusive ethos of the programme. Carers highlighted a strongly motivated desire to improve services as well as a desire to make a difference and achieve recognition as equal partners in care. The benefits to carers' self-esteem were also recognised. In only one example was the offer of pay seen as a significant motivation for carers to become involved.”

SCIE Report 28: Carers as Partners (CaPs) in social work education by Imogen Taylor, Suzy Braye and Andy Cheng, November 2009

The All Party Parliamentary Group on Social Care (an all party parliamentary group is a group of MPs from all political parties who focus on a particular issue) is very much in favour of involving family carers. They recommended that:

“ ...carers and families using services are actively involved in, and able to influence, local strategic needs assessment, commissioning, and cross-sector workforce planning and development.”

All Party Parliamentary Group On Social Care, Social care workforce inquiry 2007/08 June 2009

The group also talked about the significant impact the move to self-directed care will have on workers. They have urged local authority directors of adult social care to work with people involved in using direct payments and individual budgets to identify training needs and to develop training to meet those needs. Their recommendation is for:

“...carers and families using services to participate in the design and delivery of training and staff development, and to be properly rewarded for their contribution.”

All Party Parliamentary Group On Social Care, Social care workforce inquiry 2007/08, June 2009

The most important reasons for being involved came from family carers themselves. When we asked, they came up with a long list of skills, abilities, knowledge and expertise that they can offer. Being involved in training and workforce planning makes for better working relationships. It is a useful way to break down barriers and develop greater trust between families and workers. More than anyone else, family carers have a vested interest in getting the best possible workforce to support people with a learning disability. Family carers have a unique interest in getting things right. Most family relationships are based on love and concern for each other. Their lives are closely linked. Important choices and decisions for a person with a learning disability will also be important for their family. It is important that all decisions and choices are made with the person with a learning disability at the centre, but that the impact on their family is also considered. When things go wrong, whole families suffer.



Workforce development – what families can bring

Skills and approaches

Family carers take on many of the roles done by paid workers.

They can:

- advocate for people with a learning disability
- plan and deliver coordinated support
- promote and manage positive risk taking
- manage limited resources to deliver maximum benefit.

Family carers have learned to be realistic about what can happen in the short term, whilst staying ambitious for the long term. Families can be outcome-focused and creative. They have learned which approaches work and which don't. Most family carers recognise the importance of working in partnership. They can act as a 'critical friend', asking good, hard questions to get energy, ideas and discussions going with paid workers. Being a family carer may be just one part of who they are. For example they might be a social worker, nurse, lawyer or run their own business. They can bring these skills to the processes of workforce development.

Experience of an individual

Family carers are often a continuous thread running through the life of a person with a learning disability. They have an important role in sharing information. If a person cannot use words or express themselves in a way that others understand, close family are usually the best people to support their communication and to suggest what their wishes would be. As the main source of support, family carers know about specific conditions, and are expert in the particular needs of the person they care for.

Experience of being associated with learning disability

Families have shared the life of someone with a learning disability and this has given them experience of the wider issues. They know how public attitudes, social policy and service development change lives. Many families have been affected by these things for a long time. They can offer real-life experience of unhelpful services as well as examples of actions that make a positive difference.

Experience of being a carer

Many family carers are sandwiched between generations, both needing their support. It may be parents, partners, uncles, aunts, brothers, sisters or cousins who are caring for the person with a learning disability. Children and young people also find themselves as carers. Family members may be caring for each other, working as a team. Family carers may have disabilities themselves. Families that include someone with a learning disability can come from any social or cultural background. As a cross section of society they have an extensive breadth of experience and as family carers of someone with a learning disability they are often in the unique position of having the experience of a lifetime of caring.

Experience into strategy

It is important to involve family carers from the very beginning of developing a workforce strategy. They can play a key role in developing workforce plans to recruit the right sort of workers and to encourage them to stay working with people with a learning disability.



Involving family carers

– making it happen

Ways to involve as many families as possible in workforce development:

- **Use tools like group meetings and feedback forms**

Feedback and suggestions from family meetings, support groups, forums and open days are a simple way of giving a larger group of family carers a chance to be involved in helping workers give better support.

- **Have a pool of families to take part in specific things**

This could be writing job descriptions or interviewing staff. This does more than give a larger group of families a chance to be involved. It is very important because it can be difficult for family carers to give a firm time commitment.

- **Recognise that families have other commitments**

This doesn't mean that family carers are unreliable or not really interested. If you are a family carer you might have to help your relative at short notice. Often a health problem, breakdown in support services, transport problems, an emotional crisis or crisis of confidence can mean that a family carer is needed unexpectedly. Sometimes having to deal with these things just leaves them feeling exhausted and empty. Many family carers have paid jobs and other commitments.

- **Be prepared**

It is often difficult to rearrange meetings or interviews when a particular family carer is not available any more. Having a pool of trained and supported family carers to call on can help to overcome this problem.

- **Involve families from different backgrounds**

Some groups of family carers are less likely to be represented than others. For example, families from minority ethnic backgrounds, older family carers and family carers with a disability or chronic illness themselves are often left out. However these things can alter the kind of support that people need. People with profound and multiple disabilities, people who sometimes behave in ways that others find hard to understand or accept, (often called 'challenging behaviour') or those with overlapping problems such as learning disability and mental health problems all have particular needs. This makes it important that their family carers, as people with first-hand knowledge of what they need, can be part of developing the workforce to support them.

Developing your partnership with family carers

Here are some key points that could form the basis of an agreement with family carers related to the people you support. Many of these points underpin family involvement in general but in this case we have applied them to workforce development.

Recognition

Families want to be respected and valued. Their role in workforce development should be written into the policies and procedures of an organisation. This would show that they are seen as equal partners in care. Family carer involvement should be a key part of how the organisation works. Family carers want to be seen as equals with their point of view, alongside that of the person with a learning disability, carrying as much weight as a manager when it comes to choosing staff. When appointing staff affects them as much, the family carer should have an equal say.

Achieving the CQC outcomes

Consider how working with family carers can help your staff to keep improving the service you offer. See the table on page 15 for some ideas and suggestions. Talk to the families of the people you support and find out what they think.

Diversity and inclusion

Look at the demographics of the people you support and the people you would like to support in the future. Implement a plan to develop a group of families who reflect this and support them to work in partnership with you on workforce development.

Access to training

Family carers want to be able to get training to choose and support staff. It is important to families that this training equips them to fully participate in the workforce development role they are undertaking, for example recruitment. Providers who involve families in workforce development need to value their role by giving them the tools and support through training to enable them to have an active, positive and informed role.

Access to information, advice and guidance

Families want access to advice and support on workforce issues. This is very important for families managing individual budgets and direct payments. It is

going to be a big area for development as more and more people employ their own staff.

Financial recognition

Many families live on a limited income but this should not stop them from being part of workforce development. Even though they may not accept money they appreciate the offer. It shows that the organisation understands that their advice is as valuable as paid workers. Families may need individual welfare benefits advice before deciding whether to accept payment for their work. All family carer expenses should be paid quickly and in full.

Time commitments

Family carers are often busy people. It can take a lot of time to prepare. For example, they might have had to make alternative arrangements to care for their relative, change their own work hours, do some background reading and research or prepare a report or presentation. Family carers find it really frustrating and disrespectful when they have done all this work only to find that the meeting has been cancelled or their contribution has been cut short, or paid workers have not done their preparation. Last-minute changes leave families feeling unimportant and left on the sidelines. Sometimes these things cannot be avoided, but families need to be told as soon as possible.

Person-centred approaches and working in partnership

Consider how families work with people with a learning disability. At times there may be disagreement, but this should not mean that the views of all parties are not considered and sought, nor should it result in any party being excluded from future discussions. Effective, close and respectful communication from providers is essential to ensure that 'best interest' decision making focuses on the guiding principle of person-centred thinking and co-production.



How involving family carers can help providers achieve Care Quality Commission outcomes

There are some basic values and principles that families are looking for in relation to their involvement in workforce development. Applying these values and principles will make their contribution to workforce development a meaningful activity. The Care Quality Commission (CQC) sets out a range of outcomes that providers should be working to achieve for the people who use their service. All of the information about these outcomes is on their website www.cqc.org.uk

We have linked the values and principles that families are looking for to the CQC outcomes. This table sets out the values and principles and suggests how they could be linked to specific outcomes. We have gone on to suggest some workforce development activities that families should be involved in. Organisations including families in this way are more likely to make the most of their expertise. These activities could also help them to deliver the CQC outcomes. Organisations could use this table as a checklist to see how well they are involving families in workforce development. They could then develop policies and action plans to take this forward. Many of these values, principles and activities can also apply to the involvement of people with a learning disability.



Values and principles that family carers are looking for	CQC outcome	Workforce development activity
<p>Recognition that families have their own needs and wants – often families have to act as an advocate for the person with a learning disability. This is a special role to play. Outcomes for the person with a learning disability will have an impact on their family. This impact should be recognised and considered.</p> <p>Recognition that all families are different. The difference could be based on culture or experience. The organisation tries to involve families from a wide range of backgrounds and experience.</p> <p>Support providers produce a document that outlines their approach to family involvement. It needs to be available to families before an organisation is commissioned to provide a service.</p>	<p>Outcome 4: Care and welfare of people who use services – people experience effective, safe and appropriate care, treatment and support that meets their needs and protects their rights.</p>	<p>Families involved in:</p> <ul style="list-style-type: none"> • developing job descriptions and person specifications • shortlisting and interviewing • sharing their experience of caring for a particular person. <p>Organisation seeks to work with a range of families with differing experiences and backgrounds.</p>

Values and principles that family carers are looking for	CQC outcome	Workforce development activity
<p>Families understand the role of staff members. Workers understand that families need to be able to speak in confidence. Families need to know that they will not be punished because they have raised reasonable concerns or asked challenging questions.</p>	<p>Outcome 16: Assessing and monitoring the quality of service provision – people benefit from safe, quality care because effective decisions are made and risks to people’s health, welfare and safety are managed.</p>	<p>Families are:</p> <ul style="list-style-type: none"> • part of monitoring and evaluation • working as partners in care to make important decisions • acting as a ‘critical friend’ • sharing knowledge and expertise about assessing, promoting and managing positive risk taking.
	<p>Outcome 7: Safeguarding people who use services from abuse – people are safeguarded from abuse, or the risk of abuse, and their human rights are respected and upheld.</p>	<p>Families are:</p> <ul style="list-style-type: none"> • part of monitoring • involved in training • developing policies and procedure.
	<p>Outcome 8: Cleanliness and infection control – people experience care in a clean environment, and are protected from infections.</p>	<p>Families are:</p> <ul style="list-style-type: none"> • training staff caring for specific individuals with specific needs • involved in training staff and developing policies and procedures on these issues.
	<p>Outcome 9: Management of medicines – people have their medicines when they need them, and in a safe way. People are given information about their medicines.</p>	

Values and principles that family carers are looking for	CQC outcome	Workforce development activity
	<p>Outcome 5: Meeting nutritional needs - people are encouraged and supported to have sufficient food and drink that is nutritional and balanced, and a choice of food and drink to meet their different needs.</p>	<p>Families are:</p> <ul style="list-style-type: none"> • training staff caring for specific individuals with specific needs • involved in training staff and developing policies and procedures on these issues.
<p>There is an open and ongoing partnership with families. Not all families will be willing or able to be involved all the time but the opportunity to be involved is always open.</p> <p>Family means all its members, including the person with a learning disability. There is an acknowledgment that the person with the learning disability is at the centre, and that for many their family is in the closest circle of support around them. Everyone needs their own space so sometimes it is not appropriate to include family, but this is not the starting position.</p> <p>Family involvement is respected and valued but not taken for granted.</p>	<p>Outcome 1: Respecting and involving people who use services - people understand the care and treatment choices available to them. They can express their views and are involved in making decisions about their care. They have their privacy, dignity and independence respected, and have their views and experiences taken into account in the way in which the service is delivered.</p> <p>Outcome 2: Consent to care and treatment - people give consent to their care and treatment, and understand and know how to change decisions about things that have been agreed previously.</p>	<p>The organisation will have a proactive approach to involving families which is reflected in their values, vision and mission.</p> <ul style="list-style-type: none"> • The organisation will set out a policy and action plan in response to this report. • The organisation will have clear guidelines for staff to support their relationships with families. • The organisation will have clear guidelines to help families involved in workforce development issues. • Families will be able to access the training they may need to support their involvement in workforce development. For example, they may not have been involved in interviewing staff before.

Values and principles that family carers are looking for	CQC outcome	Workforce development activity
<p>There is a consistent approach to involving families. Every family supported by the organisation knows what to expect. They know how they can influence the development of the workforce.</p> <p>The organisation plans and budgets to support family involvement in workforce development to ensure that it is sustainable. It makes sure that families have the opportunity to be involved but are not burdened by the role.</p> <p>Family carers are listened to and their comments acted upon. There are clear objectives when they are involved in workforce development and they are kept informed of the outcomes.</p>		<ul style="list-style-type: none"> • Family knowledge is recorded, valued and used to inform and train staff. • Developing policy and practice regarding the role of families in helping people to understand and make informed decisions. • Training is delivered on an ongoing basis with refreshers and updates, not just a one-off introduction to families. • The organisation has a consistent long-term strategy or approach to involving families in training.
<p>Families understand the role of staff members. Workers understand that families need to be able to speak in confidence. Families need to know that they will not be punished because they have raised reasonable concerns or asked challenging questions.</p>	<p>Outcome 17 Complaints – people and those acting on their behalf have their comments and complaints listened to and acted on effectively, and know that they will not be discriminated against for making a complaint.</p>	<ul style="list-style-type: none"> • Using complaints as part of a balanced system of feedback. • Families are able to highlight problems via supervision, reviews, coaching or mentoring, without prejudice. • Being able to make positive comments and compliment good work. • Families as an equal partner in problem solving.

Values and principles that family carers are looking for	CQC outcome	Workforce development activity
<p>There is commitment and ownership of the value of involving family carers at all levels. Throughout the organisation there is a culture of involving families in workforce development. Everyone understands that families are important.</p> <p>Family involvement not as an afterthought but there from the beginning. Family carers should be involved in all the stages of recruitment for workers at all levels from junior worker to CEO, and involved in all aspects, including devising job roles, recruitment, training and development and exit interviews.</p>	<p>Outcome 12: Requirements relating to workers - people are kept safe, and their health and welfare needs are met, by staff who are fit for the job and have the right qualifications, skills and experience.</p>	<p>Families are:</p> <ul style="list-style-type: none"> • involved in developing job descriptions and person specifications • involved in recruitment processes • part of developing and delivering induction and other training • contributing to appraisal of staff • involved in management team meetings • involved as members of the organisation and trustees.
	<p>Outcome 13: Staffing - people are kept safe, and their health and welfare needs are met, because there are sufficient numbers of the right staff.</p>	<ul style="list-style-type: none"> • Families are contributing to policies and procedures about staffing levels.
	<p>Outcome 14: Supporting workers - people are kept safe, and their health and welfare needs are met, because staff are competent to carry out their work and are properly trained, supervised and appraised.</p>	<ul style="list-style-type: none"> • Training staff at all levels including providing case studies, evaluating training materials and devising and delivering training either as sole or co- trainers. • Clear routes into supervision and appraisal to give structured family feedback, which is gathered in a proactive way by the organisation.

Values and principles that family carers are looking for	CQC outcome	Workforce development activity
	<p>Outcome 14: Supporting workers - people are kept safe, and their health and welfare needs are met, because staff are competent to carry out their work and are properly trained, supervised and appraised.</p>	<ul style="list-style-type: none"> • Families involved in developing and delivering training. • Families devising and delivering training for personalised support packages. • Families with a clearly defined role in supervising staff working in a family home.
<p>The organisation treats family carers as equals – families are respected as partners in care and truly valued. They can see outcomes from being involved. Family carers receive appropriate training and support so that they can take part in workforce activities as equal partners with paid staff.</p> <p>The organisation recognises that the level of family involvement can change and that has consequences for everyone. There may be circumstances where support staff feel that they have more current knowledge of the person with a learning disability. However, the organisation must still recognise the importance and unique role of family in everyone’s life. The organisation values the family as a unit and the individuals within it.</p>	<p>Outcome 6: Cooperating with other providers - people receive safe and coordinated care when they move between providers or receive care from more than one provider.</p>	<p>Family carers are:</p> <ul style="list-style-type: none"> • recognised as co-providers and partners in care • included in workforce development plans • working alongside paid staff so they can learn from each other • recognised and supported as coordinators and managers of care • able to see that their contribution to any activity is valued and has an impact.

Families developing the workforce - good practice examples

We asked if any families had examples of how they have been involved in choosing, training and supporting paid staff. There was an enthusiastic response but experiences were mixed.

Some families had been involved in training GPs and other professionals. Family carer representatives on partnership boards had been involved in interviewing senior staff. Some good work has had to stop because the resources needed were no longer available.

Sadly, some families contacted us to say that they had poor experiences. For example, there were reports of ‘tick box involvement’ where families had taken part in recruitment but had been ignored when the final decisions were taken.

Here are a few examples where families felt that things worked well.

Supporting Rebecca

“ Rebecca needs one-to-one support to sustain the happy life she now lives. She has clear preferences about how she likes to live. Anyone who meets her can sense her zest for life. Her pleasures are simple and she savours them to the full. For the past 14 years Rebecca has lived in her own bungalow, in the same village as her mum and dad. They are clearly as important to Rebecca and she is to them. In common with most of us, her family are a thread running through her life and they know Rebecca as a person more intimately than anyone else. They also have the most holistic and in-depth knowledge of Rebecca’s care needs and how to meet them.

Over the years a number of organisations have been commissioned to provide Rebecca with the support she needs. Here is how Julie and Mike work with Rebecca’s current service provider:

- An advertisement is produced in a jointly agreed format.
- We have produced various information leaflets and papers which help guide the process. All applicants receive the information in an application pack.
- Prospective candidates are jointly selected for interview.
- All prospective candidates must visit our daughter in her own home. ”

“Their ability to interact with our daughter and support staff are monitored and this interaction forms part of the interview process.

- We are part of the interview panel and participate in the final selection of an appropriate candidate.
- It has been agreed that new staff will shadow experienced support workers for a period of time prior to working alone. As parents, we have produced a ‘knowledge’ booklet that covers all aspects of support, ranging from fire alarms to handling cash. The booklet is completed by the trainee support worker and monitored by the person being shadowed.
- We have been invited to attend a forthcoming four-day support worker induction programme to provide feedback from a family’s perspective.
- The support provider has agreed that we, as a family, can plan a one-day personalised induction session for our daughter’s support workers.
- One of our daughters is an approved postural care trainer and is providing training for her sister’s postural care. ”

Julie and Mike Ormian, Rebecca’s mum and dad

This clearly works well for the family and they feel that their input is appreciated by the organisation. They have developed a positive relationship where they are key players in developing support workers. Julie and Mike felt that it was very important to be able to commend good practice when they observed it. For example, they had been particularly impressed with the way two of Rebecca’s workers supported her. They knew that the organisation was keen to recognise good practice, so Julie wrote and told them. “Both of the workers received a personal letter from the chief executive. Each letter recognised what they, individually, had done to make Rebecca’s life better,” said Julie. “That personal recognition was important to them and indeed, important to us.”

The culture of the organisation and relationships with managers were also important. Rebecca’s family connections are recognised as being an important source of knowledge and expertise. Julie and Mike have developed a good relationship with local managers. It is not always plain sailing when it comes to interacting with Rebecca’s support provider, but any difficulties can be sorted out fairly easily.

“We are all in a circle, focused upon Rebecca,” said Mike. “We have talked to the support provider and they have agreed to undertake a person-centred review of Rebecca’s service. Her funding authority is also going to use the event as the main part of her service review. This has removed a lot of anxiety for us. We are now actually looking forward to the event.”

Families and self-advocates working together

The service user staff selection training and development team (SUSSTD), in north Tyneside, is a group of people with disabilities who come together to form interview panels, give presentations and deliver training to social services and other organisations from the voluntary and private sectors. Members of the team undertake a 30-week course on staff recruitment, which is accredited by the Open College. After completion of the course, participants are ready to take part in recruiting and training staff. For example, the local social services department invites the team to form separate interview panels. These panels assess applicants and their scores are combined with those from a panel of managers to give an overall result.

The group delivers presentations about the benefits of involving service users in staff recruitment to local authorities, private and voluntary organisations. They also facilitate staff team building and offer training in person-centred planning, staff selection and raising awareness. They have helped to interview social work students in Durham and Northumbria.

The team is supported by the local community access team and the training and staff development team. They coordinated the development of the training course, and are working with the SUSSTD team as they move towards becoming an independent community interest company. This will enable the team to further develop and sell their services. Ann Abernathy became involved with SUSSTD some years ago when her son Andrew, who uses learning disability services, joined the team. She said:

“I feel that an important part of SUSSTD’s ethos is to value people and support them to have a voice and to give them the confidence to use that voice, so that people listen and their voice counts.”

At first her role was purely as a supporter, but over time Ann has started to offer a family point of view. This has developed naturally through her presence as part of the team. Ann participates in all aspects of their work, including recruitment panels, training sessions and education. She is also supporting the move to become a social enterprise. “Becoming a community interest company is a big responsibility,” said Ann. “It is exciting and scary all at once.”

Ann has been able to use her experience as a family carer in several ways. Having raised two children with a learning disability, she understands the strengths and weaknesses of local support. She can empathise with families in a similar situation, although she is keen to stress that everyone has a different experience. Not every family carer wishes, or is able, to take part in staff development. Some family carers are too tired, get too little time for themselves or don't have the confidence to get involved. But Ann is keen to share her knowledge and expertise to help improve things.

“You can hear a pin drop when Ann talks to social work students about her life,” says Tony from the training and development team. “You can see the impact that she has.”

Ann works with people with a learning disability to talk to social work students at two universities. She feels that one of the most important outcomes is to break down the sense of ‘us and them’ that has characterised professional attitudes to families in the past. Families have themselves been disempowered by workers who have not acknowledged or appreciated the primary role they have in the life of someone with a learning disability.

While Ann feels this is starting to change, she acknowledges that there is a long way to go. Person-centred approaches and planning make a difference to learning disability services, but more general services have a long way to go. For example, staff in transport and leisure services could make a real difference if they were more aware of the impact of a learning disability. Ann's family have had experience of general hospital care and found that there were problems there. Having seen the impact of the SUSSTD team on other workers, Ann is confident that involving people with a learning disability and their families could make a difference. “What I would really like is to get involved with training nurses. As a former nurse myself I know that there is a lot that could be done,” she says.

A family-focused organisation

West Lancs Positive Living (WLPL) is a supported living organisation for adults with a learning disability. They are a family-led, not-for-profit organisation where all members of the board are committed to creating the best possible services for people with a learning disability. The services are aimed at promoting quality of life and social inclusion by supporting individuals and their families to have choice and control in all aspects of their lives. Some families come to WLPL when other services can no longer fully meet the needs of the person with a learning disability. This can be because they have exhausted all the opportunities available elsewhere, or because there is no viable alternative that is easily accessible.

Every support situation involves the person and their family in person-centred planning. Because of this person-centred approach, WLPL can offer access to activities that they regularly organise, as well as tailor-made options. They also work closely with other organisations who can offer support in developing work experience opportunities and micro businesses. Alongside the person with a learning disability, family members are included in defining just what support is needed. Families have been included in developing job descriptions, person specifications, recruitment, induction, training and performance monitoring. WLPL is currently looking at how to involve families in formal appraisal processes. It was clear from discussions at the meeting that families have a good relationship with WLPL.

“ In our organisation families are in charge. They own the organisation – there is no doubt that they feel they have the power and that their input is not tokenistic. I think there is nothing worse than being asked when no one takes any notice of what you say. This is a culture thing not a bolt on. ”

Tess Reddington, chair

WLPL arranges things like interviews and meetings at times to accommodate the needs of the family. Time of day, particularly when parents work, is critical to enabling the family to be fully involved. Families are entitled to claim mileage expenses and venues are chosen to suit their needs. Some families attend conferences organised by the organisation to explain the latest developments in supporting people with a learning disability, such as having a mortgage or developing a micro business. Both the organisation and the families involved acknowledge that things do not always go smoothly and sometimes support needs to be changed. The strong relationships between families, the organisation and support workers enable these changes to be made in a positive way that focuses on getting the best outcome for the

person being supported. Such situations seem to be viewed as learning opportunities for families and support workers.

“There has been a big learning curve in handing over management of my son’s support. Some of the staff are better than I am at supporting my son – a lot better. I think in future I will have stepped right away from day-to-day involvement in his care, but only when I am confident in the support service.”

Tess Reddington

It is clear that both the families, including the person with a learning disability, and the organisation can only see benefits from involving families in all aspects of developing support. The very person-centred approach makes the family integral to how the organisation operates and structures the support it provides. This approach also gives families confidence in the organisation and individual workers. The shared focus on supporting the person with a learning disability to make meaningful choices and have control over their own destiny, seems to create a real and appropriately balanced partnership between family, personal assistant and organisation.



Partnership working in the eastern region

Skills for Care in the eastern region approached the local Partners in Policymaking Network to become involved in the Expert Voices Eastern (EVE) group. This group was to act as a ‘critical friend’ to comment on the work of Skills for Care in the region. It would include representatives of people who use services directly and the families and friends who support them. EVE members were offered an induction programme so that they were familiar with workforce development issues.

The work of Skills for Care in the region is overseen by a regional committee. The EVE group has two representatives on this committee. As the stakeholder group for the region, the committee also included representatives from provider organisations of all sizes, people who commission services, Skills for Health, workforce development leads from local authorities and the regulatory bodies. The regional committee is supported by sub-regional committees and subcommittees with specific functions. The chair(s) of the main regional committee automatically has a seat on the national Skills for Care board.

As she has two school-aged sons who need extra support, Jo Hough followed the Partners in Policymaking course and became active with the regional network. The course brings together adults with a disability and parents of disabled children to develop their leadership skills. This gave Jo an opportunity to explore some of the reasons why disabled people are so disadvantaged and why many support services end up struggling to deliver helpful outcomes.

Jo said, “Undertaking the Partners in Policymaking course gave me confidence. It helped me to see that if I wanted good futures for my sons, they would need people to support them who would respect and value them as individuals. Realising this enabled me to see where I needed to focus my involvement.”

When Partners in Policymaking was approached to join the EVE group, Jo was keen to take part. After a short time Jo became an EVE representative at the Skills for Care regional committee, and was later elected as co-chair. Jo said:

“ As regional co-chair I now have a seat on the national board for Skills for Care. This has really widened my circle of influence which is a good thing. Co-chairing means that when circumstances prevent me from taking part in person, I can work with my co chair and share the work. ”

The Skills for Care perspective

“Jo has worked with us in Skills for Care for approximately five years now. Jo, in common with all EVE members, has contributed a huge amount to how Skills for Care operates in the region – and I would go as far as to say has completely transformed the way we work.

“Most importantly EVE brings the user and family carer perspective to our work, and members rightly challenge us if there is something we have not thought of.

“ This perspective is critical because workforce development should ultimately be about supporting the social care workforce to improve outcomes for people who use services and carers. ”

James Cross, Skills for Care



Families as trainers

The organisation's perspective

The Challenging Behaviour Foundation (CBF) was established by Viv Cooper. She felt, as a parent of a son with high support needs and challenging behaviour, she had no access to relevant courses that provided positive training and support for families.

There was training available for professionals and Viv, alongside her team, identified funding that allowed them to focus on developing training for families. A professional trainer and CBF staff worked together initially to identify the key things that the course for family carers needed to offer. They then brought in some families to look at their suggestions. The families completely changed the focus of the training, what it was about and how it was to be delivered. The families involved were those whose children were older, and who had been particularly supportive of the work of CBF.

One of the key principles of the training was that it needed to be delivered by two co-presenters, a professional trainer with a psychology background, and a family carer. The co-presenters worked together to decide on the structure and key messages. This training was then piloted with families, which led to several further changes. The family carer worked with the professional trainer, supported closely by the CBF. There were fairly lengthy negotiations between the co-presenters regarding the changes in order to reach a point where all were happy and in agreement.

The courses were piloted again and received 96% positive feedback. Comments from the participants included that they found a family carer delivering to families 'very helpful'. Participants found that having a family carer there helped them see how the theory was translated into practice.

The CBF, after reviewing the success of this course, felt that while they were empowering families to do things differently, they were still having to do so within the same system that wasn't geared to support their changed approach. They decided that they needed to deliver joint training, and targeted schools asking them to identify families of children with challenging behaviour. Training was then delivered to families and to school staff separately. A third training session was then delivered, bringing together the families and school staff to jointly develop positive behaviour plans. The course was evaluated by the Tizard centre.

CBF is now in the process of recruiting, supporting and training families to become trainers through their core training programme. This core training involves background to the CBF and its work, values and vision. The course is jointly delivered by a family carer, and in order for a family carer to become a CBF trainer they must do this course. The professional trainers that the CBF work with also complete this process.

If the families involved in the initial core training express an interest to go on and become trainers delivering CBF courses, they are supported by the CBF and paired with a professional trainer. Together they go through the basic training package and the family carer is supported to choose and use examples of their own experiences to personalise the training. They then go through CBF's core training package 2 on adult protection and child protection. The co-presenters then deliver the training, observed by a CBF team member who offers feedback and evaluation.

The CBF is currently training a family carer and a clinical psychologist with a background in quality assurance. They are looking to embed these approaches within CBF and maintain quality.

The family members who work as trainers are paid the same amount as the professional trainer – £200 a day. Family members who become trainers with the CBF have to be registered as self-employed and are given a handbook (developed in conjunction with families) which gives them all the information they need in relation to working for the CBF.

The training delivered is focused on what families want, and is backed up by information packs. The CBF is looking to build its capacity in terms of the number of families it has as trainers.

There has been considerable time involved in supporting families through this process. Managing the negotiation between trainers has been challenging as this, in practice, needs to be done face-to-face as the co-trainers have to be comfortable with the messages they are delivering and very supportive of one another. For the professional trainers who work for the CBF this is a very different way of delivering training, and one trainer felt unable to adapt to the co-presentation approach.

The feedback from all the training delivered has been very good, with the input of both trainers considered very positively. Some of the professional trainers said that delivering training in this way has now changed the approach they have to other training they deliver.

There has been a high investment in this process, but it has delivered the organisation's charitable objectives. The money came from the DCSF (Department for Children, Schools and Families) under their 'capacity building' grant programme, aimed at giving family carers skills and building the capacity of the CBF. The Tizard centre is looking at a longer-term evaluation of how the training has an impact on the behaviour of the children. There is now a high demand for the training.

Viv says, "[It's] such a powerful thing ... the benefits in terms of meeting the needs of the target audience are huge".

Top tips from the Challenging Behaviour Foundation (CBF)

1. Start by having a good relationship or dialogue with families and finding out what the issues are.
2. Work on developing a relationship and providing support in a way that will be helpful to families. You have to value their input highly; the feedback is so positive that the investment is worth it.
3. Continually offer support and back-up to families who are trainers.
4. Be open to listening to what families tell you.
5. It's not something you can do quickly. Take time to process and do the thinking – both with the organisation and families.
6. Be sure that you are all coming from the same place, that there is no other motivation and that you all desire to see positive outcomes.

In anything they do, the CBF get the views of families. They constantly check with the family carers they work with that they are happy throughout the process. They make sure, for example, that when families incur expenses through work for the CBF they are paid quickly. They ensure that robust protocols around training are in place and everyone is protected and supported to deliver training of the highest quality. In conclusion, Viv says that the "co-presenter approach gives a very important message to families and to professionals".

Family carer perspective

"When my son was excluded from his local school I was at a loss. I was in contact with Robina Mallett at HFT who mentioned that she had met Viv Cooper who was in the process of setting up the CBF and it might be worthwhile contacting her. When I telephoned Viv she was extremely helpful and very empathetic. I admired, respected and valued what Viv was doing and we stayed in touch.

“When Viv secured some money from the Department for Education it was to deliver training to families. I’m aware that there is a lot of investment in training courses for professionals but nothing for families.

“The CBF asked whether I’d be happy to hold a meeting at my home to explore what families would want and benefit from, regarding training in understanding and supporting individuals who challenge. I invited other families with shared interests to my home to meet with Gemma (from the CBF) and Anna, a psychologist and professional trainer. It was a feisty meeting with some disagreement. Family carers felt first and foremost that emphasis should be placed on communication ... the theme of ‘inability to communicate effectively’ ran throughout the workshops. We felt valued and listened to.

“From this and other conversations a teaching template was formed, which was initially delivered as a pilot in several places with Anna Buchanan and myself as co-presenters. We trialled in Surrey, Coventry, the Vale of Glamorgan and London. Anna and I worked closely with one another to put the material together, incorporating my personal experiences. Initially people who had signed up to attend failed to arrive, which was frustrating. So we asked families to pay a deposit which would be refunded if they attended. This worked well.

“During this period, Andy Fenwick, a learning disability nurse and self-employed trainer took over from Anna as co-presenter. Together with the CBF, the training was further developed into a somewhat different presentation.

“Viv then secured further funding to use this training to work in partnership with families and schools. We delivered *Understanding challenging behaviour* to families and schools as separate sessions. Then we brought school staff and families together to work jointly on plans to support behaviour change.



“The plan was to use the training as a research project using approximately six schools in Kent. So it was essential that delivery and content was consistent.

““ The evaluations of our training have been superb. Professionals and especially school staff have said that they valued and benefited from the training being delivered with a family carer as well as the professional trainer. A deputy head said, “[It was] like nothing we’ve ever had before, I really enjoyed the day. Made a lot more sense ... it was really great to have a mum! ””

“Throughout the training, I use personal examples of life experiences to demonstrate how having a child that challenges affects family life and to share how I’ve worked out what works and what doesn’t. The vision is that the courses will give families the tools and knowledge they need in order to identify solutions. There is still a lot of misunderstanding around why people challenge.

“I have found the ‘light going on’ moments very rewarding, plus the opportunity to work with a professional trainer – I’ve learnt from him too!

“We are paid for the work that we do. Viv feels strongly that family trainers should be equally valued. She is an inspirational person who I am always happy to support in whatever way I can.

“I believe what the CBF has achieved is unique.”

Jan Seamer, family carer co-trainer

A professional perspective

“I am a learning disability nurse working in Westminster. I worked with adults with autism and challenging behaviours, supporting people in their family homes, or in their supported living services. I felt, at times, a little isolated, so I looked for a forum to share information and good practice. I heard about the CBF by word of mouth and subscribed to their professionals email network. A group email came around from the CBF asking if anyone was interested in doing some consultancy work so I got in touch. I also have a private business delivering health and social care training. This was the start of our collaboration.

“When Anna left, I took over her co-trainer slot with Jan. It is different working with a family carer. I have to say it works fantastically well. It is so powerful for parents and carers in the audience to hear Jan’s perspective, the challenges that she faced and how she got round them. It lets parents know that they are not alone. It is something that I’d never done before but I found it natural to

work like this – it makes really good sense. I’m quite a flexible person and it works really, really well. I provide the theoretical stuff – I try to boil everything down to its simplest form, and Jan provides the reality check and the solutions. When parents come to the courses we run they often have a lot of needs; they can’t get an occupational therapist, a speech and language therapist etc. We make sure that they know that we aren’t going to be able to wave a magic wand, but we always end with a positive story. All the co-trainers have been through this process and now have really good packages for their sons and daughters. It leaves the audience with hope.

“I think historically some clinicians have used a consultative approach – they’ve talked, viewed and assessed. Working with a family trainer and listening to parents’ stories about what works and what doesn’t work has changed my whole practice. Parents are the experts – that is my viewpoint now. They may need some support, facilitation etc but they are the experts.”

“We have had 98% positive feedback from the course but occasionally a parent doesn’t get it. For a time I couldn’t understand why, and got quite frustrated, but then I realised that some people were not ready to get it. They had been so badly let down by services in their past, that it was really hard for them to get beyond those negative experiences.

“We use quite a different approach, giving families and teaching staff the skills and tools to work things out for themselves. I believe it is the best thing you can do. Professionals have given feedback that it is good to hear what it is like to be a parent – to hear how difficult it can be. The workshops are all about partnership working, and coming to a shared understanding. Professionals have said how great it is to be talking to parents in the room about what their experiences and needs are.

“I think that the training values the role of family and puts Jan and I on an equal footing. I make sure that Jan has an equal part in the training. We are both paid the same and that is very important to me, as we both have an equal input. It gets the message across to professionals that parents are the experts, they know everything about their son and daughter. That might come out emotively, but that is because they care. They may just need support and facilitation to get their messages across and heard. Parents have high expectations but why shouldn’t they? This experience has changed the way I work – I’ve now modified the language I use. A lot of trainers work alone and working alongside someone else is very different. I think that, nationally, its legacy is in raising the profile of parents as partners.”

Andy Fenwick, professional co-trainer

Involving family carers who have a learning disability in social work training

Nicki Ward is a lecturer at the Institute of Applied Social Studies at Birmingham University. Nicki spent over 20 years working with people with disabilities in a variety of social care agencies, and entered higher education for the first time in 1997 as a mature student. Her role now, as a social work lecturer, enables her to combine her interests in social work, social care and social justice. The social work programme at Birmingham University has a very good history of including people who use services and family carers in all aspects of the programme – including recruitment of students, teaching, assessment, fitness to practice and readiness to practice.

“Although some of our family carers are caring for people with a learning disability and we have some input from people with a learning disability themselves, this is more limited,” says Nicki.

The introduction of the new social work degree saw a requirement that people who use services and carers would be involved in its development and delivery. It was for universities to decide what that involvement would look like. Birmingham University sought to recruit a much more diverse group of service users and carers to support them with that work, both culturally in terms of ethnicity, but also the type of family involved. This was done by recruiting a service user or carer development worker. The worker went out to different organisations to look at the service users and carers they had worked with, to figure out where the gaps were, where representation was less good, and to recruit people to work with the programme. Nicki herself identified that there were some gaps in the range of family carers involved in supporting the work of the programme:

“[I was interested in] the way that those boundaries between carer and cared for are not always clear cut ... and the need to acknowledge and recognise that in service provision.”

Nicki met with Richard West, and Eve Rank – two carers with a learning disability who have been very prominent in raising the profile of this group. Richard and Eve are both directors of Inspired Services, and together have formed the support group Who Cares for Us? Initially Richard and Eve were

involved in a small amount of research but Nicki then invited them to be involved in teaching. Richard said, “It was good for Nicki to ask us to teach social work students about our caring lives.”

There have been two primary approaches. They have delivered sessions that were set up as modules on working with carers. They were for students who were on the adult pathway. Nicki did it jointly with Eve and Richard, who effectively took over to look at the particular difficulties carers with a learning disability have. To prepare for their input, Nicki spent an hour with Eve and Richard talking about how long the session was, the things they’d like to include in the session and who would do what. Once the framework was complete, Nicki agreed to alter the packs to make them more accessible, and Eve and Richard worked with Andrew from Inspired Services (who provides support) to develop their parts of the session.

Nicki said, “I guess in terms of support before they did it [Eve and Richard were supported for] probably only a couple of hours. But, Eve and Richard are very experienced and very skilled. I would anticipate for some other people it would need more preparation and planning. And on the day, the three of us were there together.”

The other main involvement, from a workforce development perspective, has been in assessment. The course has begun to develop specialist training called electives that students can choose to do, and one of those electives was around working with people with a learning disability. The assessment for that involved students in developing an information leaflet targeted at the group of people they’d done their elective around. Richard was involved in assessing the leaflet – whether it made sense and was appropriate to the target group. To prepare, Nicki sent them an outline of the assignment and marking criteria. Andrew was able to spend some time with Eve and Richard beforehand to make the marking assessment more accessible. Nicki felt that Eve and Richard were the best people to do that sort of assessment. Richard said “it was good and lots of fun”.

Some students struggled with the assignment and expressed concerns about the involvement of service users in the assessment. They weren’t sure if service users knew how to mark in the way they perceive academics know how to mark. Students who do fail an assignment have the opportunity to have a conversation with the primary marker, who said:

“ My response was: actually these people have been involved in producing materials for the government. This is their business. This is what they do. Maybe you didn't get such a good mark because they were a bit tough. But they certainly know what they are doing and it was done jointly, collaboratively. ”

All families and service users are paid for their time. Birmingham University's philosophy has been to have a range of payments available to service users and carers for the work they are involved in depending on the type; a sliding scale mapped against the university's pay scale for other things. “So for example the university has a recognised rate that it pays visiting lecturers per hour, so if our service users and carers are lecturing they are paid at that rate. So it is not a special rate, it's reflective of what the university's pay rates are and I think that it is a really important principle.” Payment can sometimes prove difficult and a barrier to participation because of clashes with benefits. This is the responsibility of the person to manage. The university offers advice where it can, or points people in the direction of appropriate advice around benefits.

Nicki said:

“ Generally speaking the number of hours that people are involved is quite small. And so the threshold at which it's likely to start to impact on tax and NI and other benefits. It's very unusual for people to be involved in levels of work that they would need to be too concerned about and I think they get a bit scared about the whole tax and benefits issue ... it's a matter for individuals but also one we don't need to be quite so scared about. ”

Additionally, service users and family carers are paid expenses. They get paid a fee for their time. It starts at about £21 an hour for meetings and group teaching, and currently it is about £45 an hour for visiting teachers.

The social work programme team plans its activities at different times of the day. For some people mornings aren't good and afternoons are better or vice versa. So, for things like recruitment interviews for new students, some will take place in the morning and some in the afternoon so there is a range of flexibility there for people to get involved.

For Nicki and her team, one of the key challenges has been involving a broad range of family carers and people who use services, without it impacting on the relationships they have already established with individuals who have supported their work.

“One of the important things for us is developing a broader group of colleagues with whom we can work so that we are not relying on the same people all the time. There certainly has been some criticism of the idea of expert carers or expert service users who are always the same people being asked to tick the box. So we found it very important to actually try and avoid falling into that trap and it is difficult because we have some very willing colleagues who will say yes to all sorts of things, so it is easy to become reliant on one or two people.

“As we’ve developed, a wider group of people want to be involved. Some of the service users and carers who were involved with us initially have been unhappy that they don’t now have as many opportunities as they used to. How do you maintain people being valued but avoid falling into some of those traps of relying too heavily on just a small group of people? Do you decide that you are just going to have a small group of people who you work with? We’ve been having conversations about it. I guess this is where funding could become an issue ... about whether we could develop other ways of involving some of our other more experienced service users and carers to work as mentors with people who are newly involved, with the potential to pair people up and have them work together on things. But obviously if we are going to remain committed to having people paid at a fair rate, that could potentially double our expenditure, which isn’t easy at the moment. It’s about that as well.”



Nicki has seen a big change in the perspective of the students on her course. “It’s been really powerful in confirming those sorts of things in how unhelpful it is from a service user perspective to think about these people as service users, these people as carers, these people as providers – we all fulfil those different roles at different times. [It] challenges their ideas about who people with a learning disability are and what they are capable of.

“As a whole, I’ve had feedback from a number of students and it appears in their evaluations. What they say demonstrates that we are putting our money where our mouths are in terms of collaboration. It is much more powerful to be stood at the front of a lecture or assessment session or whatever it is alongside service user and carer colleagues who are taking an equal role, than it is for us as lecturers standing there saying ‘this is what you should do’. You should work collaboratively. Modelling that behaviour is having much more of an impact on people than just saying it.”

Nicki’s experience has shown her the best way to get results when it comes to involving families:

“Planning is absolutely important. And making sure you having the time you need to plan. It is about time investment and, to an extent, it is about financial investment to demonstrate that you value the expertise that people bring with them. That’s what it is for us: ‘here are some people who have expertise that we want’ – and really engaging with people on that basis. It is about different levels of expertise and demonstrating what’s behind it. It isn’t hard and it has immense value.”

Nicki says it is hard to quantify the impact of involving family carers in terms of value for money. She does feel that the impact made by, for example, Eve and Richard, will make her students go on to be more aware in their interactions between people with a learning disability and their families. This would hopefully mean less crisis situations, which can be incredibly expensive to manage. She says, “If we can find ways to support people in their mutual caring roles, then it is going to cost the government less than paying residential care for two sets of people. If what that [Eve and Richard’s training] does is create that awareness, then hopefully it will have cost benefits in those terms.”

Family input into management teams

The organisation's perspective

Tim Jones is the south west divisional director for United Response.

“About two years ago I felt something needed to change. I headed up the south west division of United Response and the senior management team was working well, but I felt that we could work better still. All the voices on the team were paid voices and we were simply getting a paid perspective. I felt we were missing out on the voices of experts by experience – people with a learning disability and their families. We engaged in a discussion about how we might involve others. I felt that those with executive power had a duty to involve parents and advocates in sharing the responsibility for getting it right for all those who rely on us.

“We had our first divisional leadership team meeting involving people with a learning disability in January 2009, which was facilitated by an independent person. We knew that there was a gap and that other key people were missing so I talked to a number of parents and an advocate who I knew would be prepared to be part of this process. We needed a nucleus of family carers who would join the divisional team and then go back to their local areas to help set up local forums with my paid colleagues. We offered the families involved travel expenses and also paid them for their time. The outcome was that the next meeting got stuck into the meaty subject of how United Response spends its money! These meetings have now been rolled out locally to the area team meetings, and involve more people with a learning disability and families. In this way, local views, ideas and suggestions feed into and drive the divisional leadership team meetings.

“Of course, as we work even more collaboratively with families, it is imperative that we give our frontline colleagues the skills to relate well to and liaise with families. To this end, we have developed a *Working with families* training course that is being delivered across the organisation.

“ Where there are really good collaborative relationships with families in the division. There are teams of support workers who are much more engaged, involved in the problem-solving process, with better sickness records and less money spent on agency cover. Developing and maintaining a culture of involving families in workforce development matters and our ‘doing the business’ is worth its weight in gold. The chances of our getting it right for and with all those who rely on us are enhanced tenfold, twentyfold, the sky being the limit! ”

Family carer perspective

Conversation with Sue Fry, family carer involved with workforce development at United Response

Sue Fry's son Shaun is now 36 years old and lives in Bristol. Until recently Shaun was experiencing a helter skelter ride with provision – or lack of it. Shaun has Down's syndrome, is on the autistic spectrum and has complex needs. His needs are very challenging although on the surface they appear quite straightforward. Sue has been an active campaigner, action group member and a member of a Mencap group. She has also been on her local learning disability partnership board.



Shaun was in a local assessment unit and the psychiatrist wanted to place him in a residential unit. His planned three-month stay in the NHS unit ended up being five years. At the end of this period a new service provider, United Response, took over. From the beginning Sue felt that United Response sought to involve the family. United Response divide the country into four separate divisions and Tim Jones is the divisional director for the south west, the area that Shaun and Sue fall into. He commissioned independent disability advisers to speak to the families of individuals in the unit, to get their thoughts, and was really interested in their responses. United Response was very open to working with families, and Sue began to work closely with them to help develop their thinking. She worked with the manager of the service to make them see Shaun as a member of the family, ensuring that United Response supported Shaun to be the best man at his brother's wedding. Sue suggested that staff needed to do some training with families, and Inclusion South West (where Sue is a member) ran a one-day training course from the carer's perspective. Sue felt that things completely changed from there, staff saw that the relationships within the family need to be cherished.

Sue feels that Tim Jones has been very progressive in his work with families. He wanted to change the way his management or leadership team operated, ensuring that it included people with a learning disability and family carers. There has also been further training. Inclusion South West has been commissioned to run training for United Response nationally. Two sessions have already been completed. Sue feels that there is a changing culture in the organisation, and that United Response is interested in ensuring families are embedded into the organisation. She says:

“ The openness of the relationship with United Response is a revelation to me ... an organisation that's working with us – not a 'them and us' situation. ”

Sue has been on holiday with Shaun, with Shaun supported in one caravan by United Response, and Sue staying in another. She feels that the organisation is open to, and quite prepared to see, the value of working with families. For Sue, training is the key to getting this message embedded. Inclusion South West have commissioned a DVD that they use as part of the training. It gives the carer's perspective and has had very good feedback. Sue says:

“ Shaun's life is never going to be straightforward, but I trust United Response as an organisation to work with us as a family to enable Shaun to achieve his maximum potential and enjoy his life. ”

Conclusion

Pulling this document together has been a real voyage of discovery. Some families did respond to our initial request with poor experiences, which have damaged relationships between families and organisations. This was very sad to discover because the three-way relationship between service provider, the person with a learning disability and their family is pivotal. We sincerely hope that organisations who are struggling with their relationships with family carers will find something helpful in this work.

By working closely with family carers themselves, we have summarised some of the knowledge, skills and expertise they can bring to workforce development. The CQC expects organisations to work towards a set of outcomes. In the section about outcomes we have tried to show how families can help to develop a workforce capable of delivering good outcomes for people with a learning disability. We have highlighted some key issues that need to be considered to enable families to get involved and listed the values and principles families looked for in an organisation. This could provide a good starting point for organisations seeking to develop work with families.

What has been really heartening is the significant number of positive examples nominated by families themselves. There were far more than we could possibly include and selection was a tough task. We have tried to offer a diverse range of examples, across a wide range of organisations and families, however we have to acknowledge that there are some gaps. For example, it was difficult to find examples of specific work to draw in families from minority ethnic communities. We have, however, included an example about including family carers with a learning disability. We have presented examples in different ways; some brief pen pictures, some more in-depth interviews. Our intention has not been to set out the best ways of working, more to get organisations thinking about what they can do themselves.

With the development of direct payments as part of a personal budget, more and more people with a learning disability and their families will become employers. As employers, they will need to access resources to develop the workers they employ. Increasingly they will be looking at what the support organisations like Skills for Care and Skills for Health have to offer.

However, not everyone will choose to use a personal budget to employ staff directly. Where they look to an established organisation to provide staff this will present a different set of challenges. Employers could see a significant increase in staff working alone in a person's home, perhaps for only a few hours per week. This will mean developing new ways of supporting and

developing such workers. Perhaps working together creatively with families will provide some useful models.

Clearly there is some really positive work going on to involve family carers of people with a learning disability in workforce development. We hope that this work will inspire and support organisations to take this further into the future with all the challenges and opportunities it is bound to present.



Acknowledgements

We asked families to let us know about their experiences of working with organisations to develop their workers. We had over 50 responses and we would like to thank everyone who responded to our request. We have included a number of examples in some detail, so we would like to extend particular thanks to:

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West Midlands Family Carers
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Our advisory group:

Stephanie Chapman, National Valuing Families Forum
East Midlands representative
Jo Hough, National Valuing Families Forum East representative
Barbara Coles, Families Leading Planning
Cath Baker, Princess Royal Trust for Carers/Crossroads
Caroline Farnes, National Family Carer Network

The authors

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Lucy Virgo works for Mencap as the families and communities project manager. She too has worked in many different capacities, from local community development work, to forming national partnerships and influencing policy. She has been involved in a number of projects for Mencap focused on families and has developed work around BME families through the *Reaching Out* and the recent *Is Information Enough?* reports.

References and resources

We have read a lot of information and spoken to a lot of people in the process of putting this pack together. We would like to thank all of the people and organisations that have helped us.

We have quoted directly from some documents, such as:

- SCIE Report 28: *Carers as Partners (CaPs) in social work education*, www.scie.org.uk
- *All Party Parliamentary Group On Social Care Social care workforce inquiry* 2007/08 June 2009 (See General Social Care Council website www.gsccl.org.uk)
- *Valuing People Now: a new three year strategy for people with learning disabilities* 19 January 2009 Department of Health, www.valuingpeoplenow.dh.gov.uk
- *Scoping Study: The Involvement of People with Learning Disabilities and Family Carers in Workforce Issues* by Alice Bradley
- *Strategy for the Participation of Carers in Skills for Care Work*, www.skillsforcare.org.uk
- The Care Quality Commission Outcomes, www.cqc.org.uk

There are also some resources that can help you to work more effectively with families.

Afiya Trust - Diversity in Diction www.afiya-trust.org.uk

Putting People First - Carers and Personalisation – emerging practice, an online resource <http://www.puttingpeoplefirst.org.uk/Browse/Carers/>

Skills for Care - Eight principles for involving service users and carers <http://www.skillsforcare.org.uk/nmsruntime/saveasdialog.aspx?IID=377&sID=101>

Carers matter – everyone’s business www.skillsforcare.org.uk

Social Care Institute for Excellence (SCIE) Carers as Partners (CaPs) in social work education <http://www.scie.org.uk/publications/ataglance/ataglance19.asp>



a positive partnership between The Princess Royal Trust for Carers and Crossroads Care



all about people