Carers and Personalisation – Improving Outcomes

Hosted by: York Carers Centre

Venue: York CVS, Priory Street Centre, 15, Priory St, York, YO16ET

14th February 2011

Workshop Programme

The workshop will introduce and focus on the main themes of the Department of Health's recently published "Carers and Personalisation – Improving Outcomes" by Bernadette Simpson and Robin Murray-Neill.

10.00 – 10.15	Registration and coffee
10.15 – 10.30	Welcome (Frances Perry – York City Council)
	Introduction to Workshop (Bernadette Simpson & Robin Murray-Neill)
10.30 – 11.30	Workshop 1 (Speaker – Stuart Brown – Carer)
	Carers as Expert Partners & Whole Family Approaches
11.30 – 12.30	Workshop 2 (Speaker – Linda Stubbs – York Carers Centre)
	Early Intervention and Prevention
12.30 – 13.15	Lunch
13.15 – 14.15	Workshop 3 (Speaker – Barbara Booton – Carers & Personalisation Trainer)
	Making Self-Directed Support Processes Work for Carers
14.15 – 15.15	Workshop 4 (Speaker - Nigel Devine – Social Care Consultant)
	Market and Provider Development
15.15 – 15.30	Top 3 issues from each table

Workshop 1- Carers as expert care partners and whole family approaches

General: you may find the carer, but not know the user, perceptions of principal carer and family may vary- who are the family? A network. Avoid making assumptions about acquiescence- can be problematic. Additional complexity when carer and cared for person live in different Local Authorities. NB encourage the carer to talk about 'A Life of My Own'.

This works well:

- Personalisation process has supported the identification of carers and the integration of support. Community and voluntary sector supporting the self-assessment process or professional supported
- Choices between joint/ separate/ not at all assessment
- Carers' specialist services
- Strong carer voices in co-production- can change views, services & partnerships with PCT
- Listen to former carers too
- Recognising the uniqueness of the individuals caring needs
- Treating the carer as the expert
- Involving carers on boards- supported by professionals, carers taking lead and driving the agenda
- Having reference groups that feed into partnership boards
- Creation of carers registers at GP surgeries
- Consistency of contact and good communication with key care worker/ GP's/ advanced practitioners who clients trust (sadly this is an exception)
- Genuine commitment by assessors to move towards better ways of working
- More networking between voluntary/ statutory agencies
- Consistency of contact with the carer and service user and health care professionals
- Community / voluntary sector support self-assessment
- Over recent years, young carers profile has improved, recognising the care they provide within families
- Society as a whole understands the term 'family carer' much more now.
- Carers working together
- Carer organisations working well together (in York)
- Family and user led organisations
- Pool of PA's (list held by Calderdale Council)
- Use of carers centre staff to help with carers assessments

This needs to change/improve:

- The assumption that the carer and cared for live together- No reciprocal arrangements across Local Authority boundaries- dependent on goodwill- when carer & cared for person are in different Local Authority areas
- In some contexts, the voice of the carer/ family can be heard over that of the service user
- How do you hear what the carer really needs/ wants- need a situation of trust- is this possible in a joint assessment?
- Still a lot of professional led assessment- how do we shift to a shared responsibility?
- Some parts of community & voluntary sector appear to foster dependency

- Difficult to capture what I want and feel on a form- and then the challenge to respond
- Everybody needs to buy-in – still a way to go.
- Historic difficulty to engage GP's. GP's need to look at carers needs e.g. carer given tablets for bad back- real issue was that lifting caused bad back.
- Constant changes in staff- management of change needs to be improved
- Good communication network needed between frontline workers
- Carers not recognising that they are carers
- Educating all leisure services
- Authorities i.e. police to raise awareness around caring responsibilities understand/ supporting universal services to understand their responsibility around carers
- Hiding behind confidentiality- advance statements need to be utilised to a greater extent
- Professionals need to involve carers more when crisis impacts
- Need to recognise carers' expertise.
- More time to listen to carers- they see the cared for in a 'normal' context- health professionals see them in an 'artificial' situation- the cared for may present quite well
- Carers need to be aware of their legal rights. Recognise the carer's right/ choice not to care
- In North Yorks, carer gets the assessment forms via post to fill in!
- Care workers need training, but this must be appropriate based on the person being cared for
- Carers not involved in assessments
- Most care workers only interested in the money
- Lack of knowledge sharing between professionals
- Training by carers- of professionals
- Leadership- recognition of carers needs to come from the top
- The whole family approach needs to be trained into the system
- Carers need to be in at commissioning level- tender/ co-production
- Culture- social work staff attitudes and ways of working
- Some BME carers reluctant to use services
- Language used e.g. carers assessment should be called carers 'need's assessment/ carers support questionnaire
- Preventative work with carers- providing information & support before a crisis develops

Actions:

- Need to reinforce the language to distinguish between paid & unpaid carers
- Raise profile and public discussion of carer needs
- Move to a shared responsibility
- Raise awareness/ change culture- more involvement from GP's on partnership boards and taking responsibility for changing attitudes
- Involve carers in hospital discharge
- National incentives for GP's to engage with carers/ raise issues on GP consortia board
- Could local link groups provide an interface?
- Carers want a key named worker to set up support services
- Look at the design of the assessment
- More flexibility in organising assessments e.g. evenings/ weekends- personalised approach
- Look at case studies to pass on positive messages of PB's working well.
- Register of PA's

- Family and user led organisations need to collaborate more and work closer together
- PA training/ support and supervision
- Changes to social work staff culture
- Carers’ needs assessments should be offered separately from the cared for person but it should be a choice
- Culturally relevant services and support
- Use of language and jargon
- More emphasis on prevention
- Moving assessment focus away from hours spent and towards impact on cover

Workshop 2- Early Intervention and prevention

This works well:

- In York: more literature available about key resources available from CYC, carers centres, other public services e.g. libraries, hospitals
- More collaborative working which raises awareness generally
- Hospital signposting to carers centre
- Outreach to different communities (e.g. BME)
- The range of support and advice in the voluntary sector
- Carers centres. Generalist at first contact, specialist information along the journey- there is an accreditation for information standards and an ability to focus on the carer
- Information timely (not overloaded at the start)
- Info in easily refreshed format
- GP door knocking YHIP funded project to raise awareness
- Planning for continuity in 'crisis' situations- i.e. forward planning for carer illness etc.
- Planning to keep people in work etc.
- Supporting carers to make informed decisions- whether currently accessing services or not.
- Advice worker in surgeries to signpost carers
- Getting carers support in primary care services
- Providing information/ tools to carers so they can navigate system
- Having a dedicated carers information service
- DVD for young carers
- Carers centres working with GP practices
- Pilot project in Calderdale at GP surgery around early intervention
- Young carers' cards
- Calderdale- Gateway to Care- telephone number signpost to relevant council widely advertised
- York schools project- Early intervention fund, run by care centre. Worker goes into school assemblies/ classes and supports young carers to come forward and raise awareness
- Having funded workers, especially specialist (i.e. Learning Disabilities, Young Carers)
- York GPs providing information about carers centre and role
- Personalised transition process project in York

This needs to change/ improve:

- Keeping information updated and distributed
- Coordination of information
- Resources- investment in prevention-people to intervene early. Raise awareness
- Rehab services- carers to be involved alongside (not 'do for')
- Pharmacies- e.g. Boots have refused to allow the Carers Centre to display leaflets!
- Better awareness of range of support- professionals
- Capacity issues? Identify hidden carers, but what if we can't offer support or service?
- Duplication of information
- Hospital staff need to be more aware
- Scope to work regionally or sub regionally in partnership with and between carers' centres to raise standards?
- Feedback response indicates lots of information gaps still exist

- Widen awareness across the community – primary care (including receptionists), libraries, police, school nurses
- Misperception between sign posting and data sharing
- Move away from ‘if it doesn’t work, call me back’ approach to planning for changes and variation
- Employers need to recognise which employees also have a caring responsibility
- School teachers involved in signposting young carers
- Keeping information up to date
- Reaching more front line professionals
- Raising awareness, then not being able to meet the need
- Government providing information in accessible format.
- Marketing of carers centres- make people aware they exist
- Making sure people don’t feel judged or ‘a burden’
- Lack of support to prevent isolation/ trauma
- Need more funding for carer centres to prevent carers being passed from pillar to post
- Carers being refused lower level support e.g. cleaning, ironing etc.
- More funded time to raise awareness of carers
- Using local media to highlight carer issues
- Calderdale GPs need to see carer work as part of the core role

Actions:

- Accessing places that carers go to distribute key information about resources e.g. pharmacy, GP, supermarkets, libraries etc.
- Raising awareness of carers needs at times of key discussions e.g. hospital discharge, initial assessment at social services, GP visit etc.
- All workers at all levels to have carers’ awareness training
- Investment in prevention- outreach workers
- Early intervention- wider community regarding carer recognition
- Keep emergency card on agenda and working effectively
- How do we do best for carers at commissioning level?
- NHS to be a full time partner, primary care should encourage carers to seek support
- Support people to recognise that they are carers
- Front line workers- proper utilisation of GP carers registers
- Carry out staff census to find out which employees have caring roles
- ‘Pop up’ providing information on government / local Gov. websites
- Younger peoples website- face book etc. with pop ups.
- Continue to be creative
- Invest to save in low level intervention
- More emotional support to be available
- Free newspapers or council publications a good way to reach a lot of carers
- Make carers assessments have a legal duty to assess when requested in line with community care legislation ‘Duty to assess’
- Sufficient resources for 24/7 support (out of hours)
- Carer to feed into YCC and Calderdale employment strategy
- Carer assessment- when and how it integrates into whole support plan

Workshop 3- Making self-directed support processes work for carers

3.1 First contact

This works well:

- Carers' champions
- Carers reference group and Expert by Experience group in York has potential if supported from the top

This needs to change/ improve:

- Information for carers about carers' services
- Information overload
- More identification of carers by GP and on hospital wards on admission rather than at discharge

Actions:

- As above (More identification of carers by GP and on hospital wards on admission rather than at discharge)
- Information on personalisation- worded better

3.2 Assessment

This works well:

- Skilled workers supporting young carers through assessment in a supportive and non-threatening way. Well trained
- Using terms people understand when doing supported assessments to help identify carers at an early stage and checking they are happy with what they are doing
- Improved relationship between partners
- N Lincs. – Carers able to ask anyone to help self-assessment
- Good relationship with carers support centre- dedicated carers support team
- Partnership working carers support workers and care assessors
- Carers assessment can be done before cared for person- benefits in doing it this way as can pick up if there are needs for support/ services

This needs to change/ improve:

- Funding for personal budgets for carers to ensure they can have a life outside the caring role
- Consistency of approach, enabling good practice to be rolled out
- Clarity around expectations- not raising false hopes, but explaining honestly about what can be achieved.
- How to support carers who want to say 'no' but find it difficult
- More flexibility in approach needed- personalise the process
- Clarity about parent carer's assessment- not always happening
- Assessment and resources coming from it are based on what carers currently will provide- pressure on carers to continue if not able to challenge this

Actions:

- Greater awareness raising around the contribution carers make to society highlighting that carers aren't costing us money, but saving us a fortune
- Encouragement to all carers not to feel guilty for having a life of their own
- Using putting people first website to share good practice info e.g. terminology, assessment wordings etc.
- Clear pathways and processes for assessments- flexible, personalised and linked
- Avoidance of assumptions- more training

3.3 - Resource Allocation

This works well:

- Specialist workers- rolled out training across different teams
- Innovative thinking via RAS in York
- Web tutorials from legal perspective of PB's

This needs to change/ improve:

- Confusion as to what RAS can be spent on
- Training and advocacy for carers should be included in RAS
- Innovative work not being done
- Still too prescriptive on what spend money on- rather than 'here is the money, work out how it is spent to meet need'.
- Financial assessments- contradicting what SW say can have
- Reviews are changing what was agreed drastically

Actions:

- Local Authorities move away from block contracts
- Better training for S Workers
- Consult with carers and service users as to what want from personalisation/ for the future
- Look at case law coming through on personalisation
- RAS needs to work for everyone- not just the strong willed/ proactive carers

3.4 - Support Planning

This works well:

- Good practice in North Yorks links assessment of carer and cared for
- Locally in York- 'Lives Unlimited' starting to support local people to support plan
- Son's life transformed through individual budget
- Independent living scheme (scheme that supports carers through process)
- Forums that work with voluntary sector to identify and listen to them in terms of what works well with support plans

- Asking voluntary organisations to be a conduit in terms of sharing info with VOS brokerage- explaining options

This needs to change/ improve:

- Family approach- work with ‘Younger Families’ so culture changes
- Old systems which separate carers and cared for
- Support plan for whole family- cared for person currently owns support plan
- Carer cares for three people- has three carers assessments!
  No RAS until carer’s assessment/ needs identified
- How to support people to support plan
- Funding supporting people to support plan
- RAS needs to include brokerage/ support to support plan
- Systems in Local Authorities cause barriers
- Carers need to be informed about independent living as an option
- Recruitment and retention of support staff
- Carers need a variety of support to navigate services when comprehensive care package is required
- Ensure that options discussed with carers re: SD/ PB if declined this needs to be revisited to keep option open
- Clear definition of what outcomes will be and how measured
- Partnership working between voluntary sector and larger organisations to ensure local knowledge is retained and pertinent

Actions:

- Funded (pilots?) monitor and evaluate and plan towards cohesive service- but need support planning to be part of provision
- Need to change culture and mind-sets in terms of care plans- language
- Looking at voluntary organisations- delivery of support that social workers would normally be expected to undertake

3.5 - Review

This works well:

- Annual reviews for SU/Carers are scheduled annually or when circumstances change
- Service user reviews are picking up new carers
- Within Local Authority feedback from assessors, gaps in service provision can be fed back to commissioner

This needs to change/ improve:

- Emergency plans/ services can be very expensive when there is limited take up
- Coordination of feedback from reviews across all organisations

Actions:

- Reviews being undertaken within different organisations- information feeding back to a central point

- Targeting of resources to reduce waiting lists for review e.g. telephone reviews, use of partner / voluntary sector organisations

Workshop 4- Market and provider development

This works well:

- Good commissioner/ provider relationships in some areas
- Representation on planning boards in Bradford and Rotherham
- ‘Shaping the Market’ events in some areas
- Link in York have the potential to help in this area
- Peer support e.g. ‘Looking After Me’ courses for carers
- Carers Advisory Groups and Carers Partnerships facilitate constructive relationships and dialogue with carers to ensure they have input into strategic developments
- Carers are on partnership boards and are making recommendations
- Formation of Carers Board
- Electronic call monitoring for the care workers
- Carers Advisory Group: East Riding- mostly made up of carers (they have a say)
- Individual service funds, especially for older people who don’t want to employ staff or take a personal budget
- Role of Carer strategy manager

This needs to change/ improve:

- Wide variation in stages nationally- consistency needed
- Joint strategic commissioning/ strategies needs to involve more carers
- Evidence base for Carers Needs has to improve
- Lack of proper training of some agency staff
- Lack of regulation around PA’s
- Lack of appropriate support and services for service users- this needs to increase in conjunction with support for users
- Statutory providers need to work with carer groups to support the development of self-sustainable groups
- Better understanding of personalisation (people don’t want the extra responsibility of a personalised budget)
- We need a realistic plan/ strategy- things won’t change overnight.
- More transparency/ consistency in care provision
- Where is the incentive to improve for providers who are doing it for profit?
- Crisis management
- More engagement & consultation with carers regarding services, right from the start
- More focus on how the market can be encouraged to develop
- Thinking traditional services are the only options
- JSNAs being easy to read

Actions:

- Training on co-production both on individual budgets and service and organisational developments
- Joint Strategic Needs Assessment- must prioritise cars in their own right- not dementia/ MH add ons
- Raising awareness and aspirations of carers around services to meet their needs
- More training for PA’s and service providers

- Market position statements need to be developed by local authorities, voluntary organisations, carers and service users- we need to know where we're at before we can move forward. Need to identify gaps.
- Education for the providers 'you need to do better'
- The need for an honest broker
- Moving to framework agreements, not block contracts
- Whole range of suppliers who have signed up to the framework agreement gives carers choice
- Keep post of Carer Strategy Manager and move into general council (not Adult Social Care)
- Carers to lead the challenge to service providers

Personalisation and carers- Key priorities for action to improve outcomes:

Priority	When	Who
Message to DoH & Gov- carers should be protected in their own right. Cascade to local services	ASAP	This event DoH/ Gov
Awareness raising/ training for and about carers in universal services	On-going	DoH/ Gov organisations
Provide resource for carers local specialist services		LA/Gov/PCT/HSC
GP's need to see carers as part of their core business. Identify GP carer champion (GP with caring responsibilities?) GP's on partnership boards	ASAP	All
Information, communication and training are key- all levels from top-down. Involve carers in on-going review	1-3 year plan? Involve Carers ASAP	Health and Social Care management teams
Personalisation is about the needs of the individual/ carer and choice- still need quality public service provision (LA /voluntary sector)		
Ensure information is clear, jargon free delivery in a timely manner. Apply for information standard Access information through digital TV	Next 12 months	Region
Early intervention/ carers assessment first	Hospital admission	NHS-CYC senior managers Medical practitioners Carers Centres
Revisit what personalisation means Training, planning, step-by-step	Now	All Health Care management
Resources pool of PA's available	Now	Agencies Voluntary sector
Clear, accessible information about carers' legal rights	ASAP	Local authorities to work with appropriate VSO's
Create an information 'hub' in each area		
Co-production in planning and commissioning services, recruitment and selection, support planning and providing services	Now	LA, Support Groups, Care Providers, Carers/ peer support
Listen to all family carers		
Collaborative working/ networking		
Review membership of Carers Strategy Group and Terms of Reference		
Planning around people's lives as citizens, not round services		
Managing the transition from block contracts to IB's without losing valuable local services		
Manage transition from young carer to adult carer, ensuring age appropriate support		
Communication- flexible, co-produced, accessible, plain English, co-ordinated		
Develop 'champions'- individuals, local providers, local authority staff		