Carers Co-Production Event Report

November 2017

West Dunbartonshire Health and Social Care Partnership hosted a Carers Co-Production Event on 30th November 2017, chaired by Beth Culshaw Chief Officer of the Health and Social Care Partnership.

This event was facilitated by the HSCP alongside partners from the multi-agency Carers Development Group to share the progress of the last year and to ask for carers views and comments on the work undertaken so far.

Attendees to the event included carers, young carers, 3rd sector partners and HSCP managers coming together to learn and hear from carers about their own experiences of caring in West Dunbartonshire.

Councillor Marie McNair, Convenor of the Health and Social Care Partnership's Integrated Joint Board, welcomed attendees and provided an insight to her own experiences as a career.

An overview of the Act was given by Claire Cairns from the Coalition of Carers in Scotland to help set the scene from a national perspective and this was followed by Beth Culshaw providing an update on local progress and introducing the workshops.

Kirsteen McLellan, Integrated Operations Manager, provided an overview of the Scottish Government funded pilot based within the Community Hospital Discharge Team and the trialling of the Tier 1 Carer conversation based on the local learning from West Dunbartonshire's Falls Collaborative. This programme of work is supported by wider community health and care services and by Carers of West Dunbartonshire.

Workshop sessions were facilitated by integrated operational managers from across adults, older people, addictions, mental health and children services; with carers and carers' organisations being represented at each table.

This report describes the feedback on each of the following areas and will inform not only the local Carer's Strategy but also the development of eligibility criteria.

- A - Adult Carer Support Plans
- B - Young Carer Statements
- C - Eligibility Criteria
- D - Duty to provide support
- E - Short Breaks Statement
- F – Priorities for Local Carers Strategy

Workshop A - Adult Carer Support Plans

Each table was asked to consider the following statements:

	Table top feedback
Statement 1 Informal assessment and planning may be enough for some carers and other may need additional information to contribute to the formal assessment for an Adult Carer Support Plan	Every plan should start with an informal engagement and this should be recorded as of importance, take time at a) first statement, incrementally increasing information offered at 1 to 1 (not just in leaflets)
	It is important that carers have access to early conversation about what is going on in their life and how they can be supported
	Depends on who does the assessment and their experience
	What does “informal” mean, don’t feel this is adequate
	Agree with this statement
	Agree an informal assessment may be enough
Statement 2 Assessment and information gathering is a shared responsibility and should involve carers, practitioners and carers representatives as appropriate.	Respite availability and range of common sense solutions including concessions for local amenities leads to improved carer wellbeing
	Collaborated information from family and relevant others need to be included
	Statement 2 word “should” is not helpful
	Agree with this statement
	Agree with statement 2 provided consent is given at time of assessment
Statement 3 The processes and systems of assessment and information gathering need to be simple, accessible and user friendly.	Various media types needed for carers not just leaflets, TEC example of a DVD as an alternate resource of learning about what is available
	Yes agree but need to promote services that are available, especially if not involved with social services

In addition to the specific statements above each table provided feedback on other areas for consideration when preparing Adult Carer Support Plans, these comments are summarised below:

- In carrying out assessment be realistic about what the budget is
- Mental health is an issue - Support for complex mental health conditions
- Support from Y Sort – it, are they equipped to deal with young people with disabilities?
- Assessor needs to know details of carers' role, not just what they see when doing assessment – 24hr view
- Assessor being active in saying what is available
- Everybody is different and the cared for person's condition can and does change - Reviews should accommodate changes to need
- Financial impact on carers
- Right of advocacy missing – the act still maintains gap – lack of information based on carer knowledge and financial ability to progress POA etc.
- Carer should have a copy of informal assessment
- 1 to 1 relationship between the carer and HSCP staff (who has a checklist) of issues that you should check up on
- GP and health information for carer need to have full information re changing medical needs/medicines management, especially cross border information sharing
- Information- early on a diagnosis e.g. dementia to act at point of crisis
- Issue of payment for some aids and the difference between owner occupier and those in social rented houses, needs better communication
- Informal chat is a starting point but personal outcomes to be identified – this should not be a tick box exercise
- Assessment of needs to be followed up

Workshop B - Duty to prepare Young Carer Statements

Two of the tables out of 6 covered this topic. One of these tables was made up of a number of young carers, staff from Y Sort-it the local organisation in West Dunbartonshire who support our young carers and staff from WDHSCP whose role involves working with Young People. The feedback captured is detailed below. Each table was asked to consider the following statements:

	Table top feedback
Statement 1 Informal assessment and planning may be enough for some carers and other may need additional information to contribute to the formal assessment for a Young Carer Statement	All the tables agreed with this statement
Statement 2 Assessment and information gathering is a shared responsibility and should involve carers, practitioners and carers representatives as appropriate.	All the tables agreed with this statement
Statement 3 The processes and systems of assessment and information gathering need to be simple, accessible and user friendly.	All the tables agreed with this statement

In addition to the specific statements above each table provided feedback on other areas for consideration when preparing Young Carer Statements?

- Concern over the role and the young person but the group did not feel this was their area of expertise due to the demographics of the group
- I want a menu of options that are open to me displaying the rang of what is available
- DVD of what you have involved in and how it has changed my life
- If I could continue to … my dream is …and this will sustain me as a carer
- The assessment is a conversation about matching my need with making something available
- Respite being imaginative and meaningful in conversation
- Budget to make a decision
- Whole family involvement in the process of developing support
- Involvement in the process may be difficult due to the age of the child e.g. primary age and their understanding
- Young carers statement within education handbooks
- Assessment tools need to take into consideration age of the child and be accessible
- Skilled assessors - important to take time and identifying needs which may exist out with that identified by carers themselves

Workshop C- Eligibility Criteria

All 6 tables discussed this topic and the feedback is detailed below.

	Table top feedback
Statement 1 Eligibility Criteria seems an appropriate way to determine if a carer is eligible for support	Agreement on eligibility criteria should trigger actions to inform/discuss to carer the range of options available – included in this should be information on community concessions, cinema, leisure centre
	Statement agreed across the group
	I need to know if I am eligible then I will receive a service
	I need to know the substance behind the criteria
	Are criteria reflecting the self-reported impact of the caring role?
	Who is ineligible – would absence of a diagnosis be an obstacle?
	We need to be careful that if carers don’t meet the eligibility criteria that doesn’t mean they are not a carer
	Overall comment on eligibility criteria – agreed as a common sense approach is needs to take into account resources available and capacity of professionals
	Eligibility criteria – professionals have a role to avoid support plans that create undeliverable support through lack of resources, capacity to provide support
	Eligibility criteria cannot be narrow or restrictive in its focus
	Eligibility criteria needs to take into consideration that some Young Carers may not qualify for appropriate benefits e.g. Carers Allowance or the role maybe split across siblings for example so do not individually meet the minimum requirement to be classed as young carer
	In respect of young people the eligibility should be identified within the GIRFEC principles and needs met/barriers removed
Statement 2 Carers should have easy access to good quality supports from a range of organisations including HSCP, voluntary carer services and wider community including support groups.	Agree - Support does not always need to be from statutory services – it is about how we use the whole community
	Statement agreed across a number of the groups
	Yes – to access carers centre, access to carers meetings
	Eligibility criteria needs to capture impact of carer

Statement 3 Support for carers should be based on supporting them to meet their outcomes.	Needs to be recognised that Young Carer outcomes may be met within services either within college for example through Leisure/Social groups that are available
	Statement agreed across a number of the groups
	what does “outcomes” mean – is this about carer wellbeing or about them meeting their own needs
	Transport – support for carers – should unpaid carers get same access as paid carers to reduced/free transport
	Support access – all workers have different ways of working – SW to have information – makes carers conversations a crucial process
	What areas of carers’ life are affected? Good practice within the guidance for outcomes
	People often don’t know where to go for support/help – link to lack of publicity of carers services

In addition to the specific statements above each table provided feedback on other areas for consideration when preparing our Eligibility Criteria?

- Health – physical
- Living environment e.g. housing
- Future Planning
- Emotional wellbeing
- Finances
- Relationships
- Cross boundary issues, of living in one area and caring for someone from another area
- Need up to date information on what is available. Carers need to know about all resources and how to access them
- Opportunities for sharing information on relevant supports at time of diagnosis of the cared for person or at time of carer assessment
- Comprehensive knowledge of cared for persons condition is essential
- Reviews are crucial – to reflect changes in need an adapt care support plans timeously
- Needs to ensure “unmet need” is noted and requires highlighting both individually and as a service – becomes part of the review
- Need to capture assessed need and want or potential future need
- Separate the carer role and needs for person cared for and the needs of the carer
- Where needs identified then support plans should be developed within Education and shared as appropriate with teachers particularly within secondary
- Should an individual be deemed not to meet criteria then what review/appeal process will be in place?

Workshop D - Duty to provide support

All 6 tables discussed this topic and the feedback is detailed below.

	Table top feedback
Statement 1 Carers support should be personalised and carers should have choices about the support they receive, who provides it and when they receive it.	Agree – Carers should be given a range of choices regarding care/support provides, preferably at time of adult support care package formulation. Delivery of support and timing of should be led by carer to meet needs of carer and cared for person
	All statements agreed upon
	Should carers have choice – YES – But do carers feel that they have a choice?
	Need conversation and imagination to explore breadth of what could be available and the outcomes you want to achieve in lif
	What does the carer want from life, how do I support the carer to maintain own sense of identity as a person
	Agree with all 3 statements
	Positive to have choice – seeing more with SDS – Need increased choice going forward more flexibility i.e. some people getting put to be too early
	Opportunity to maintain normality e.g. funding for bespoke personal care (times/flexibility/blocking time/targeted to choice
	Agree but carers support should be flexible (not rigid) is not AM, PM. Homecare services need
Statement 2 Under the power to support carers, carers should continue to have access to good quality supports that maintain, sustain and improve their lives without having to have an Adult Carer Support Plan and a need to be assessed for eligibility	Should be access to good quality support without a full support plan being competed, early intervention, multi-agency working and information sharing and educating others – shared partnerships between different LA possible
	Agree – Support should be available as required and may be light touch/less formal and should not require to be underpinned by a bureaucratic process. Information on this type of support has to be readily available
	Carers feel there are gaps in services/supports. Should be a community response to improving access for disabled people – mapping exercise looking at this for a carers perspective.
	Agree with all 3 statements
	All statements agreed upon
	Good identity of supports and services to all
	Every local authority will run different services/supports in the community – will there be continuity?

Statement 3 Confusion about budgets and support funding can be confusing for carers; this may lead to anxiety due to being worries linked to benefit entitlements and/or charging arrangements	Agree – Carers experience is of finding out by chance/word of mouth or info from carers centre. Help available through money advice Centres letter/forms difficult to understand at times. Welfare rights very good.
	All statements agreed upon
	Budgets do not appear to be transparent
	Difficult to understand implications of finances and own monies and how much I have to pay towards my care. Need support to understand finances
	Budgets and supports – training issue for professionals, importance of duty SW being aware, need connection with welfare rights entitlement and SDS process and understanding of it. Benefits can be difficult to understand.
	Agree with all 3 statements
	More age appropriate information linked to benefits you can receive
	Clearer guidelines around what benefits affect what other benefits, who can apply for what
	Assessment required when accessing public funds? Numbers, who manages this?
	Shouldn't be restricted just to people who receive carers' allowance

In addition to the specific statements above each table provided feedback on other areas for consideration when working with carers and carer organisations about levels and types of support.

- It would be good to have more groups for disabled young people
- Transition issues – when young people reach 18yrs doesn't seem to be as much support available.
- Age issue – Carer responsibility goes beyond pension age and some carers financially disadvantaged
- Discharge process involves carer but admission process seems like the carer is not as involved as at discharge
- State of health – to get to know this about the person and how they are to help inform the development of care around the person
- Connectivity/Communication – Link cared for and carer – ensure conversations happen as needs of cared for person changes – Shared information, system to track through and support carer to understand changing roles
- If conflict of interests – need to deal with this this so crucial to have connectivity and crucial front line staff having these conversations with carers
- Examples of quality supports driven by assessment - (tier 1 and tier 2). Scheduled review/triggered reviews. Tier 1 recorded including self-management at this tier. Agree point of trigger review

- Need agreed review timescales and accountability to be appropriate with current support program
- Future and emergency planning required – carers centre always offered, not necessarily at HSCP
- Online and control – Care support plans on line, understanding of access e.g. continence and available services information. Possible use of APP to be updated, responsive personalised choice permissions
- Carers' emergency plan would be adaptable for this APP
- Support examples – reduced paperwork and pressures this creates – support should not be burdensome – need to reflect carer needs/abilities
- Shared corporate responsibility and connectivity to right professional advice – welfare rights

Workshop E - Short Breaks Service Statement

All 6 tables discussed this topic and the feedback is detailed below.

	Table top feedback
Statement 1 When care packages are designed for the person who needs support these should include carer support that allows carers to have a break in care.	Yes agree – Conversation needs to include Imagination, flexibility, personalisation and transition process for young carers.
	Out of the Blue service offered by Carers of WD
	Agree – Carers need to be satisfied that respite really meets the needs of the cared for person.
	Respite/short breaks can mean very different things from carer to carer, family to family
	At the time of diagnosis support has to be available to support carers and cared for person through that adjustment It has to be part of the journey
	GIRFEC – Getting it Right for Every Carer
	Agree with all 3 statements
	Not about providing substitute care, more about enabling the carer to continue what they are doing
	Yes agree – Break is required for carers
Statement 2 Services and information about options need to be accessible and available when needed	Short Breaks Statement – a meaningful, clear statement is needed. Needs to be kept up to date, by whom? How will carers know about it? What info should it contain?
	Resource list of what is available to me for short breaks e.g. arthritis car, hotel etc.
	Statement 2 Personal/family choice has to be respected but family carer choice can be influenced by the availability of information on the different respite options
	Agree with all 3 statements
	Identified possible issues with regards to available/accessible resources that provide the short break
	Publishing a directory of support services – how can this be accessible to all?
	Are carers aware of the options re breaks in caring? – What are the details re timescales for planning for this – RESPITE Bureau
	Definition of a short break – everyone sees this as something different

Statement 3 Carers recognise that quality care i available but nothing can replace the care that they can provide	This does sometimes feel as though we are not working in partnership and it can be an uphill battle
	Agree with all 3 statements
	Carers need to be given permission to prioritise respite
	Carers need to be supported to feel comfortable with the respite provision.
	Quality of care being available e.g. taking away on holiday an link to respite co-ordination
	Requirement for good quality care providers
	Agency staff – is there a protocol to ensure these staff are trained appropriately

In addition to the specific statements above each table provided feedback on other areas for consideration when developing the Short Breaks Service Statement.

- Short breaks should be bookable well in advance
- What about recording stories when caring role is not working?
- Highlighted that at present it is the responsibility of Young Carers to arrange replacement cared for the person they are caring for so they can access an activity or service provided by Young Carers service. We need better links with SW with regards to delivering this in the future. Take some pressure off Young carers so that they can enjoy the experience.
- Will the same options be available to Young Carers? SDS options
- Ensuring fit for purpose paperwork – challenges of practitioners gathering financial information – clarity required for practitioners
- Need to further explore role of SDS and financial framework
- Difference between 2 types of funding for SDS and LA funding
- Use of respite budget flexibility to meet needs
- Framework – availability and flexibility within financial framework and policy – needs consistent guidance and framework and policy agreed.

Workshop F Priorities for local Carers Strategy

All 6 tables discussed this topic and the feedback is detailed below. There was less feedback on this topic and this may have been due in part to time constraints and tables not getting the time to consider this topic as fully as some of the others.

	Table top feedback
Statement 1 There should be one Carers' Strategy for all carers in West Dunbartonshire	Young Carers have different issues to those of adult carers and this should be clear in any local strategy that is written. As long as this is done one strategy for all carers would suffice
	Yes Agree
	Agree with all 3 statements
	Agree with all 3 statements
Statement 2 Young Carers' needs must be considered within GIRFEC model and align with Children Services Plan	Makes sense
	Agree with all 3 statements
	Agree with all 3 statements
Statement 3 A one page Getting it Right for all Carers should be available for our citizens	Yes agree
	Agree with all 3 statements
	Agree with all 3 statements

In addition to the specific statements above each table provided feedback on other areas for consideration when developing our local Carers' Strategy.

- What should be in it? Training staff to understand their responsibilities within the Carers Strategy
- Needs to be tangible
- Accessing an assessment can be difficult and need support to understand who I do go to discuss this
- Anticipation of ongoing care is happening
- Communication about discharging people from service
- Recruitment is an area of concern, staff not rewarded properly for their role
- Admission/discharge – How do you plan admission and what about planning for unexpected - Anticipatory care planning how to ensure it is recorded?
- Transparency over admission/ACP for mental and physical health
- Unscheduled care

The table below highlights other key themes that arose during the table top discussions

	Table top feedback
Information for Carers	Poor information between hospital and GP carers felt responsible for communication, - traumatic and stressful.
	Could a card or something be developed so that carers are told early about what support is available.
	We need to be told what is available and clarifying what the journey is
	Carers need to understand avenue for WDHSCP – Carers of West Dunbartonshire- Carers should have this information at point of diagnosis
	Conversation – giving information but not overloading people at first contact, flexibility for people to choose
	Carers telephone line needs to be highlighted and better publicised
	Basic awareness when taking on caring duties – GP's, Chemists
	Key point identified the lack of publicity of what carer services are available
	Staff seem to focus on their own individual roles – "Carer gets lost". Carers still "stumbling across information"
	Carers centre have made progress but not everyone knows about it – how do we share information about the carers centre better?
	Transition for Young Carers to Adult Carers needs to be carefully considered and planned for local developments in this area within Y Sort-it for example
	Information for young people to help identify themselves as young carers where appropriate is required as well as professionals e.g. SW, teachers, GP's etc.
	Indicative budgets – assessed hours and indicative budget Not all services available will require a budget/cost
	I want to know a budget exists
Identification of carers	Flag on patient record that I am a carer
	Carers may not identify as carers
	Identifying support to Young Carers enabling them to remain at home is important
	Early identification and referrals to services such as Y Sort-it is critical - support and information in achieving this required for professionals e.g. teachers
	Clear plans for Young Carers are important and need to be known to teachers
	Identifying carer and cared for person separately – separate needs identified and therefore in paperwork and financial pathway e.g. based on cared for persons financial records and linked to cared for persons record and bill/charge and not carers

Carers Experience	Booking respite care is not possible too far in advance (July next year for a family wedding). Need to check with respite bureau
	Holidays – can't book respite too far in advance for annual holiday
	Overnight stay – carers need to have confidence in the staff staying for overnight stay – peace of mind especially if they have had a bad experience of staff falling asleep when on duty and caring for someone
	Emergency placements at respite bureau seem to be ok but there is a reliance on someone else agreeing to drop their perioc of respite to accommodate the emergency admission
	Used to have dates provisionally sent out but this seems to have altered
	Guidelines required for people working in people's homes – client could be put at risk if carer not awake
	Respite being available to work with my diary so that I can plan my holiday
	Respite – "being flexible about what I can use as respite"
	As a carer I do not feel an equal
	Lack of resources to ensure staff know about carers' role and how they should be treated with respect
	Transition across services, young adult, feeling there is a lack of continuity across disciplines, sharing my story 18/19 – it is a cliff
	Carers often feel they are not recognised or listened to
	Feel I am not being treated with the respect as a carer who is an expert by experience
	Carers would have appreciated chance to review statements in advance of the event
	GEOMEC – GREATEST EXPERT ON MY EXACT CIRCUMSTANCES
	Carers experience of not really being listened to
	Supplies for maintenance of skin conditions and personal care/hygiene
	"Caring can be relentless – it does affect your mental health" – becomes part of your life.
	Employment – can impact on your ability to work – "No way I could hold down a job"
	I may be eligible but I receive no fund for holiday, pension
	Being a care should be self-reporting, this is what is happening
	"Has to be more carers' centres"
	Allow carer to be themselves – remove the guilt
	Dignity and human rights - continence pads disposal e.g. people in shared closes/bin areas etc. – neighbours being aware of personal health issues
	Daytime carers excellent but night time carers and weekend carers seem to be very different i.e. "Night and Day feeling" regarding Homecare service and this was collaborated around the table. Is Agency staff used at weekend/nights? Training issue?

	Home carers not giving client prepared meals left for them
	Home carers and issuing medication – case of 10 day course which took 18 days to deliver due to night time carers not giving medication. Service have been asked for an explanation but no feedback to family
	Sometimes Homecare do not return telephone calls when someone phones to raise an issue
	Care needs to be consistent across all staff
	If night services (Carers) in place then this impacts on the family carer as they have less faith in these services
	Also issues of missed visits from Homecare or just buzzing to see if client is in/ok but not actually going into the house
	Filling in false stuff in the client book – this was reported by the family carer
	Agency staff failing in job – is this a training issue? What are our quality assurance systems around staff supervision and client satisfaction?
	Male/female carer sometimes the gender makes a difference to client especially with dressing/undressing tasks and putting clients to bed
Respite	Day opportunities for respite
	Transport to geographically based service
	Respite as a support to transition from family/home based care
	Sharing of how others have used respite

Next steps

This report will be presented to the Carers Development Group for consideration and discussion and to inform our work going forward. The Carers Development Group will then determine how it is to be cascaded and publicised and any other possible action to be taken as a result of the report.

The content of the report will be used to inform and develop our local carers' strategy and to finalise our eligibility criteria prior to its publication. We will use the report to shape and develop our Adult carer Support Plans and Young Carers Statements. We will continue our pilot work within the Hospital Discharge Team and report to the Scottish Government as required.

We will report and update our Integration Joint Board with our work on implementing the Carers (Scotland) Act and ensure our senior managers ongoing commitment to the Act.
In addition we will continue with our work and provide ongoing support and training to our staff to ensure smooth implementation of the Act.

Finally, we would like to extend our thanks to all of those involved in attending the co-production event and for making it such a success, your support is much appreciated.