## ADDITIONAL INFORMATION AND PRESENTATIONS

**7 SUPPORTING CARERS IN THEIR CARING ROLE**

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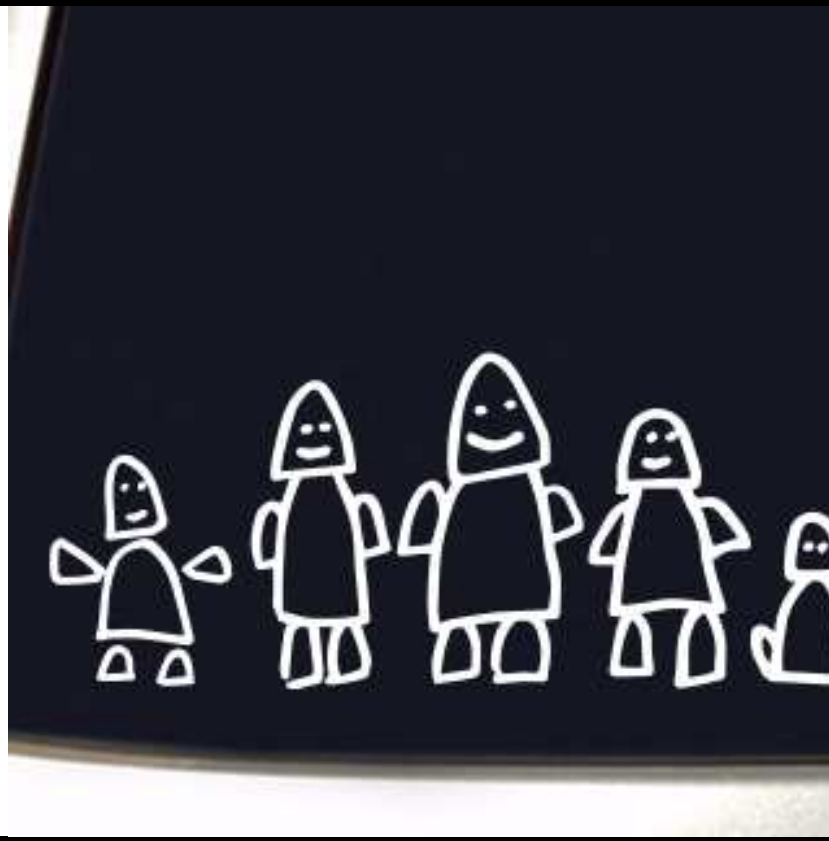
# HYCA



## HAMPSHIRE YOUNG CARERS ALLIANCE

# WHAT IS HYCA?

The Hampshire Young Carers Alliance (HYCA) is a consortium of ten Young Carer projects/services within Hampshire.



HYCA was formed around 2005 with the initial objectives of individual projects/services working closer together, sharing good practice & resources. The overall aim and vision was to develop a single county-wide voice, advocating and championing Young Carers across the county.

The consortia has allowed stronger relationships to evolve with key stakeholders, ensuring an overarching aim of ongoing quality, consistency and sustainability moving forward.

Hampshire Young Carers Alliance

# BREAKDOWN OF PROJECTS

ALL INDEPENDENT: ONE PROJECT IS PART OF A NATIONAL CHARITY, FOUR ARE LOCAL YOUNG CARER SPECIFIC CHARITIES AND THE OTHER PROJECTS FORM PART OF OTHER LOCAL CHARITIES WITH BROADER REMITS.

| | | |
|---|---|---|
| **Andover** | • Andover Young Carers | *Young Carers Project* |
| **Basingstoke** | • Basingstoke & District Young Carers | *Young Carers Project* |
| **East Hants** | • The King's Arms | *Independent Youth Charity* |
| **Eastleigh** | • One Community | *Community Voluntary Sector* |
| **Fareham & Gosport** | • Kids | *National Youth Charity* |
| **Hart & Rushmoor** | • Hart Voluntary Action | *Community Voluntary Sector* |
| **Havant** | • Off the Record | *Independent Youth Charity* |
| **New Forest** | • Community First New Forest | *Community Voluntary Sector* |
| **Romsey** | • Romsey Young Carers | *Young Carers Project* |
| **Winchester** | • Winchester & District Young Carers | *Young Carers Project* |

# WHAT IS HYCA?

**hat size of area does HYCA support?**

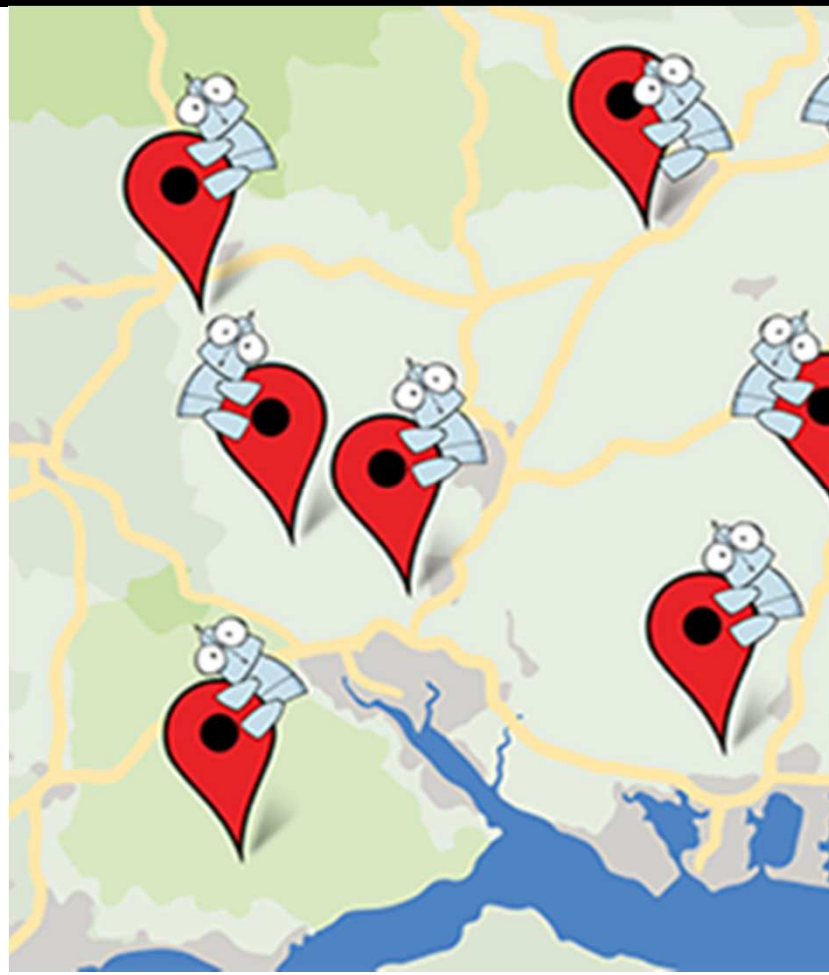
- 3,700 km2
- Both rural and urban areas

**ow many Young Carers are there in Hampshire?**

- 4,109 Young Carers identified in the 2011 Census.

**ow many Young Carers are supported through YCA?**

- 1,272 registered as Young Carers on the projects
- 1,449 supported over the year 2019-2020



# CURRENT PRACTICE

Project response and delivery takes into consideration geographic, demographic and area need.

A countywide, consistent approach in managing referrals, reviews and 'step-down' process.

Shared database and tools in reference to measuring Young Carer outcomes, giving both qualitative and quantitative data sets.

Strong links to Hampshire's Children's Services Family Support Service, with appropriate challenge made from both sides.

Referrals come from a multitude of sources including self-referrers and family members.

Joined up approach and collective response to identified issues/barriers across all aspects of Young Carers needs. This can include internal and external factors.

Stronger links with Hampshire's Adults' Health and Care Department ensuring that conversations relating to Carers involve Young Carers.

# AREAS OF FOCUS

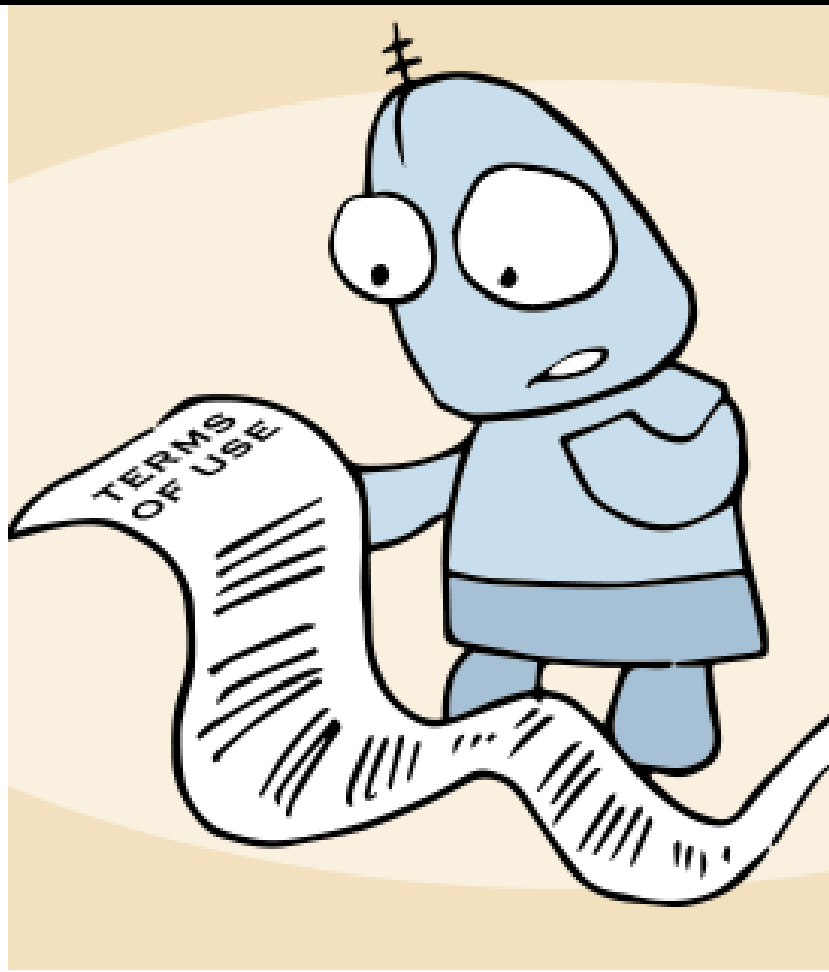
Ongoing consistency in school response – whole school approach.

Stronger links with ‘Health’ to ensure their understanding of Young Carers, both in what their needs are and in how their role reduces the impact on their services.

To maintain a ‘non-hierarchical’ relationship with Hampshire County Council, ensuring referrals, and particularly transitions from CSD to AHC, continue to be reviewed and improved.

A joined-up approach in sourcing potential funding and in use of volunteers.

Revisiting and retaining a model of a Young Carer’s representative group that is involved in the decision making processes relating to Young Carers in Hampshire.



# QUESTIONS?

**Thank you.**

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# Personalised Care and how it can help to support young carers and adult carers

Alison Froude
Delivery Partner
Personalised Care Group

NHS England and NHS Improvement


**The NHS Long Term Plan** - People will get more control over their own health and more personalised care when they need it.

Personalised Care is one of the top 5 Priorities

# What is Personalised Care?

Personalised Care Video

# Personalised Care: A shift in relationship between health and care professionals and people.

Being seen only as a **patient with symptoms** or separate conditions that need treating.

SHIFTS TO...

Being seen as a **whole person** with skills, strengths and attributes as well as needs to be met.

Being asked 'What's **the matter** with you?'

SHIFTS TO...

Being asked 'What **matters** to you?'

Being **told** what is wrong with you and how your health needs will be met.

SHIFTS TO...

Being valued as an **active partner** in conversations and decisions about your health and wellbeing.

**Not having** the information and support you need to make informed health and wellbeing choices and decisions.

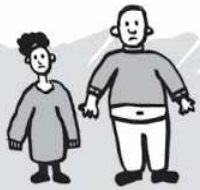
SHIFTS TO...

Having the information and support you need to make **informed choices and decisions.**

Feeling **powerless** against a complex health and care system.

SHIFTS TO...

Working in partnership with health and care professionals and **sharing power**.



A **'One-size-fits-all'** approach to meeting your health and wellbeing needs.

SHIFTS TO...

Having more **choice and control** so your health and wellbeing needs are met effectively in a way that makes sense to you.


Health and care professionals believing **they have all the knowledge**, expertise and responsibility for your health and wellbeing.

SHIFTS TO...


You and your health and care professional **sharing knowledge**, expertise and responsibility for your health and wellbeing.

Having to tell your story **again and again.**

SHIFTS TO...

Only needing to tell your story **once.**

This illustration was developed by the Personalised Care Strategic Coproduction group.


1. Working in partnership with my clinician & wider care team
Shared decision making
2. Choosing from the available options
Enabling choice
3. Building my knowledge skills & confidence
Health coaching & supported self-management
4. Connecting to help & support in my community
Social prescribing
5. Designing my own plan supported by professionals
Personalised care & support planning
6. Managing my own budget & support, with help if I choose
Personal health budgets & integrated budgets
WHAT MATTERS TO ME

# 6 Components of Personalised Care

1. Shared decision making
2. Enabling choice, including legal rights to choice
3. Social prescribing and community-based support
4. Supported self-management
5. Personalised Care and Support Planning
6. Personal health budgets and integrated personal budgets

# Personalised Care Commitments
## in the Long Term Plan

1. People will get **more control** over their own health, and **more personalised care** when they need it
2. Personalised care a part of **business as usual** for the health system
3. Roll out a comprehensive model of personalised care to **2.5 million people** by 2023/24

**Personalised Care & Support Planning** – over **750,000** people expected to benefit with a shift to a different conversation

**Social Prescribing** – **900,000** people to benefit by 2023/24

**PHB** - up to **200,000** people will benefit from a PHB by 2023/24

**Health inequalities**: personalised care can be **targeted** to meet the needs of individuals who experience health inequalities click here

# What does this mean for Carers ?

Personalised Care implementation plan has three actions specifically that focus on carers:

- Action 2 – take a whole family approach
- Action 13 - explore new rights to have personal health budgets for carers
- Action 14 - test, gather best practice and build the evidence for PHBs for carers; Identify actions on how the Personalised care model works for carers, working with relevant representative organisations.

# Personalised Care and support planning – a different conversation !


- Carers are entitled to request a carer's assessment, which is separate to any assessment of the person they care for and takes account of their needs, as a carer.
- Following the assessment, a carer can hold a support plan in their own right to support them in their role of providing care
- Personalised Care and support planning is a opportunity for the carer to identify their needs and the outcomes most important to them .
- It is crucial that this plan is based on what matters to the carer !
- Once the outcomes have been agreed they should agree the best solutions or actions to achieve these outcomes.
- **The actions or solutions in the plan maybe be different to what has traditionally be offered!**

# Personalised Care and Support Planning - **Changing the relationship**


If the person they care for has a Personalised Care and Support Plan the carers should be fully involved, as far as the person wants them to be,

*in line with criteria 1: people are central in developing and agreeing their PCSP including deciding who is involved in the process.*

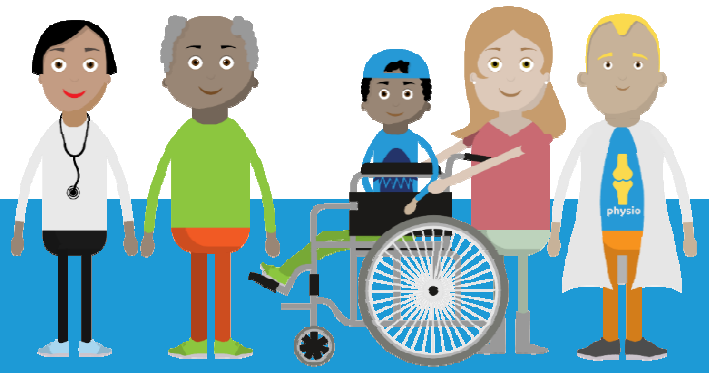
# Personalised Care and Support Planning Best Practice Example

Portsmouth Carers Service

- The assessment and support planning model they use is in line with the Key Features of Personalised Care and Support Planning
- They also offer personal health budgets via prepaid card direct payment

Support to Carers includes:

- Wide range of breaks options e.g. weekly coffee, break away, hair/beauty services, sports/crafting/hobby equipment, part payment for gym membership, kindle, TV subscriptions
- Replacement care includes 6 hours a week sitting service or equivalent via direct payment,
- Telecare/tech based solutions



# Social prescribing- Connecting people to help and support in the community

- Carers should have access to social prescribing in all areas of England through referral to a social prescribing Link Worker from primary care and other agencies such as local authority social care teams. This includes both adult carers and young carers.

- Carers should be proactively identified as a group that may benefit from social prescribing approaches.

- Social Prescribing Link workers  should understand what a carer is, the challenges they may face with managing their health and wellbeing, and understand what services exist in their local area that cater explicitly to carers, alongside wider services, groups and activities that may be of benefit.

# Social prescribing

# Best Practice Example


- A 70 year old man was referred by his GP to the Social prescribing link worker; suffering with anxiety, fatigue, sleeplessness, he was the main carer for his wife who was registered blind.
- The primary concerns were issues with preparing meals, his wife refused to attend local luncheon clubs as she did not want anyone to see her drop food on herself,
- As a consequence her husband was missing social interaction as he had always been extremely socially active and a member of his local church
- They developed a plan focused on the main cause of anxiety which was meal preparation.
- They arranged for the local lunch club to prepare meals for collection to be eaten at home they also sourced a local organisation who provided daily freshly prepared meals on a china plate which just need re-heating.
- They also supported the patient to search for additional meal purchasing/preparation options online.

# Personal Health Budgets


- To give people greater **choice, flexibility** and **control** over the health care and support they receive

- An opportunity for people to work in **equal partnership** with the NHS about how their health and wellbeing needs can best be met

- Personal health budgets are **not about new money**, but about using resource differently

- This could range from  a small one off payment or a much larger budget to support ongoing care needs

# Personal Health Budget

## Best Practice Example


- Sasha is an 8 year old young carer who helps care for her brother Karim who has cerebral palsy and mother Meena who has mental health problems.
- Sasha has to spend a lot of time helping at home and with the Covid-19 pandemic there have been even fewer opportunities to play with friends and have time to just have fun .
- The family's care coordinator talked with Sasha about what's important to her and what's working and not working for her.
- She said she missed going to playgrounds and spending time outdoors. She said there was little to do that's fun at home and in their garden.
- The care coordinator discussed with the family how they might use a small amount of money to help the family spend time together playing and have fun.
- They agreed that some garden play equipment would make a big difference to them all and allow them to have more fun together.
- A personal health budget was used to purchase a playhouse and swings that both Sasha and Karim could use.
- This has helped support the health and well being of the whole family.

# Personal Health Budget

# Best Practice Example

Mrs W cares for her husband who has dementia and a heart condition, he has no formal support and she has her own health issues and has recently had two knee replacements.

As the caring has become hard for her to manage alone, they had moved in with their daughter and her family for support.

A carers personal budget of £300 was awarded to create a garden area for them so she has somewhere to get away from her husband if she needs a break but is still within earshot if needed.

Having her own space to potter and relax will increase her emotional and physical wellbeing, and gives their current living situation more chance to work out long term, reducing the need for formal support eg a package of care or full-time dementia specialist care home.

# Supported Self Management


- Supported self-management focuses on ‘what matters’ to the person, so they are seen within the context of their whole life, including their relationships, interests and caring responsibilities.

- It is about supporting the person they care for to improve or maintain their health and wellbeing as much as possible

*and just as important …*

- It is about supporting the carer themselves to improve or maintain their health and wellbeing as much as possible

- Where needed, it is about developing the knowledge, skills and confidence and could involve: health coaching, peer support or self-management education.

# New Roles in Primary Care

## Health & Wellbeing Coach

- Can work with a carer to identify what's important to them, set personal goals and appropriate steps, build skills and confidence to achieve goals, and use problem solving to work through challenges.
- They can  support carers by working with them to develop their knowledge, confidence and skills to take control of their own health and wellbeing and to do more of the things in life that brings them joy.

## Care Coordinator

- Can work with a carer to ease the potential burden of navigation and coordination across multiple health and care services.
- These roles will work with the carer to support them and may direct them to one of the recognised supported self-management interventions:  health coaching, peer support and self-management education.

# Best Practice Example

## Care Co-ordinator


- A care coordinator worked with a lady with arthritis and osteoporosis which were causing her mobility problems. She also had diabetes which she seemed to be managing effectively.
- Together with her husband, she had recently moved from her previous home over 40 miles away.
- She was now a long way from her children and grandchildren and reported that she lacked in confidence and struggled with anxiety.
- The care coordinator spent time with her talking about ways to help her manage her own conditions, and at the same time, care for her husband.
- They looked at how she could batch cook, so she could heat up a healthy meal quickly without much effort if she was in pain or lacking energy.
- They also discussed using technology such as a tablet to keep her mind active.
- It would also help her to keep in touch with her family.
- In this way, she started to identify ways she could change her behaviour and develop her skills.

# Best Practice Example

## Peer Support

- Peer support helped a person with dementia and their carer have more honest conversations.
- Supported by a link worker they explained it was hard to even get anyone in the door because he was fearful of ending up in a care home and didn't want to be diagnosed.
- He was trying to give the impression that he was coping by hiding things from his carer.
- The carer and link worker got him along to a peer support group.
- Once he met others living with dementia, he heard about strategies to help him keep living at home.
- It opened a conversation with his carer to be able to support him better.

# Active Connections: Young Carers Accessing Sporting Opportunities

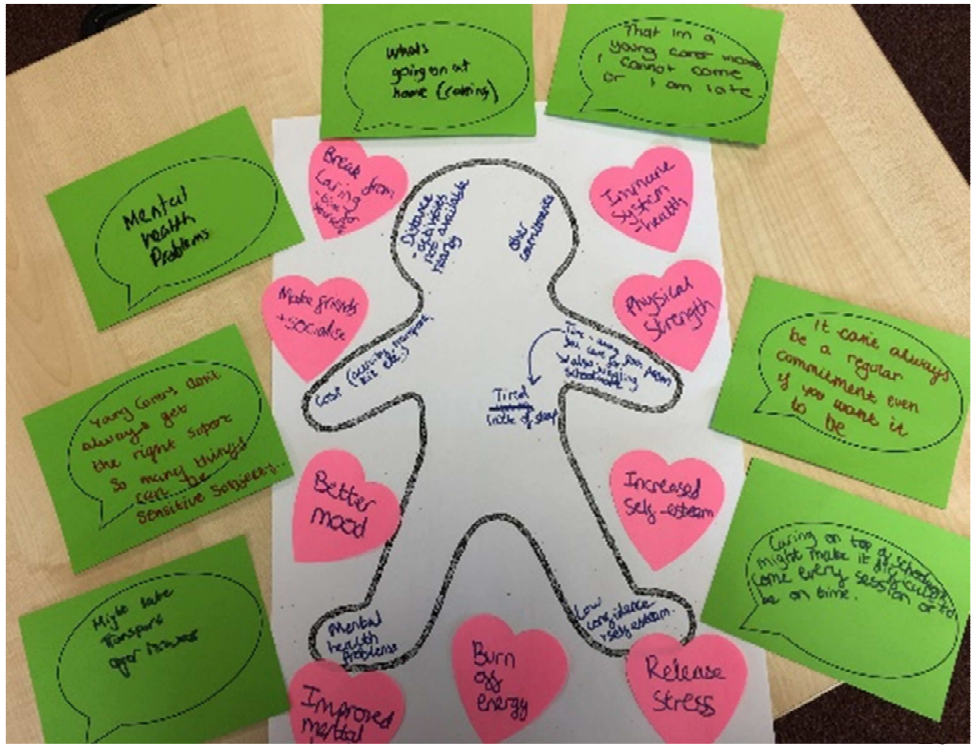
# Barriers that young carers face when accessing extra-curricular opportunities

- Lack of time
- Caring responsibilities
- Unaffordable
- Lack of transport
- Anxiety, worry, lack of self-confidence
- Having additional needs
- Struggling to make friends
- Having no energy or motivation
- Worried about being judged

*I just can't juggle it all'*
*'I'm not able to get out that often'*
*'I worry about what is going on at home'*
*'I don't have anyone to take me'*
*'I'm scared something is going to happen and then I can't care or help at home'*

# Benefits that young carers notice when regularly engaged in extra-curricular physical and group activities

- ✓ **Improved mental and physical health**
- ✓ **Time to myself / headspace / respite**
- ✓ **Make new friends**
- ✓ **Healthier lifestyle/fitter**
- ✓ **Better sleep**
- ✓ **A happier me!**



# Personal Testimonials

‘Climbing has made my confidence higher because I’m around other people my age and we’re challenging each other’.

‘The biggest impact to me is that I talk to people more easily now’

‘The biggest difference it has made to me is that I am now more physically fit’

‘Climbing has taught me to push myself to do things I didn’t think I could’

‘I swam to the deep end, achievement of the week!’

‘I like dance because it lets me get away from caring for my sisters and it relieves my stress’.


Questions

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# Personalised Care and Strength Based Approach – how it works for carers.

Southampton Carers Scrutiny Inquiry

Moraig Forrest-Charde and Louise Ryan

# What is personalised care?

Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths, needs and preferences.

**Comprehensive model for personalised care**

1. Shared Decision Making
2. Personalised Care and Support Planning
3. Enabling Choice
4. Social prescribing and community-based support
5. Supported self-management
6. Personalised health budget and integrated personal budgets

Making personalised care an everyday reality for people requires a whole-system change through the systematic implementation of all six components, supported by key enablers that deliver the necessary redesign to make the model a reality

# Personalised care – Southampton's View

| Measure and what it is | What will it look like |
|---|---|
| **A. Patient activation measure (or equivalent) - People completing a measure which helps illustrate how engaged they are in managing their condition** | Services more able to identify the right kind of service for an individual. |
| **B. Self-management - People given access to services/Apps which assist them to manage their condition** | A more informed person with the tools to manage their condition |
| **C. Community – based support - People referred for social prescribing community groups, peer support and similar activities.** | Access to wider support from like minded people or people who have had similar problems themselves |
| **D. Personalised care and support plans - 'People have proactive, personalised conversations which focus on what matters to them, delivered through a six-stage process and paying attention to their clinical needs as well as their wider health and wellbeing.'** | A plan which considers a persons wider wellbeing including 'what matters to them' and their support network |
| **E. Personal health budgets** | More people given choice of how their PCSP is delivered, personalised to their and their support network. |

# Social Care Strengths Based Conversations

- 3 conversations has been adopted as an approach for assessment and care planning within Southampton.
- The first conversation explores an adult's strengths, and connect them to personal, family or community resource that can offer support.
- Within that conversations with family/cares  and involvement is key.

# 3 conversations

- The 2nd conversation is led by the adult to assess risks in their lives and to plan for any crisis that may occur.
- The 3rd conversation is planning for long term needs and outcomes. Based on what a good life looks like to that person. Drawing on resources available including personal budgets, personal skills and community assets.

# These conversations are suitable for Adults and Carers

| Conversation | Needs assessment and care planning questions |
|---|---|
| 1. Initial contact | •How can I connect you to things that will help you get on with your life –based on your assets, strengths and those of your family?<br>•What do you want to do? |
| 2. If people are at risk | •What needs to change to make you safe and regain control?<br>•How can I help make that happen? |
| 3. If long-term support is needed | •What is a fair personal budget and what are the sources of funding?<br>•What does a good life look like?<br>•How can I help you to use your resources to support your chosen life? |

# Personalised Care

Carl Adams, Head of People Participation/ Clincal lead
Community Specialist Service, Solent NHS Trust

25th February 2021

# Approach

- Services and staff personalised care improvement programme

- **WASP** tool - COM- B model survey

- Action based on learning from ‘we said’ vs ‘what we do’ vs ‘what others say’

- Working on improvement series of improvement, training
  - Community Independence Service, COPD, Diabetes

- Repeat survey to learn impact

# Current improvements

## Personalised care and support planning

- Regional workshop (one page bio)
- Therapist goal planning

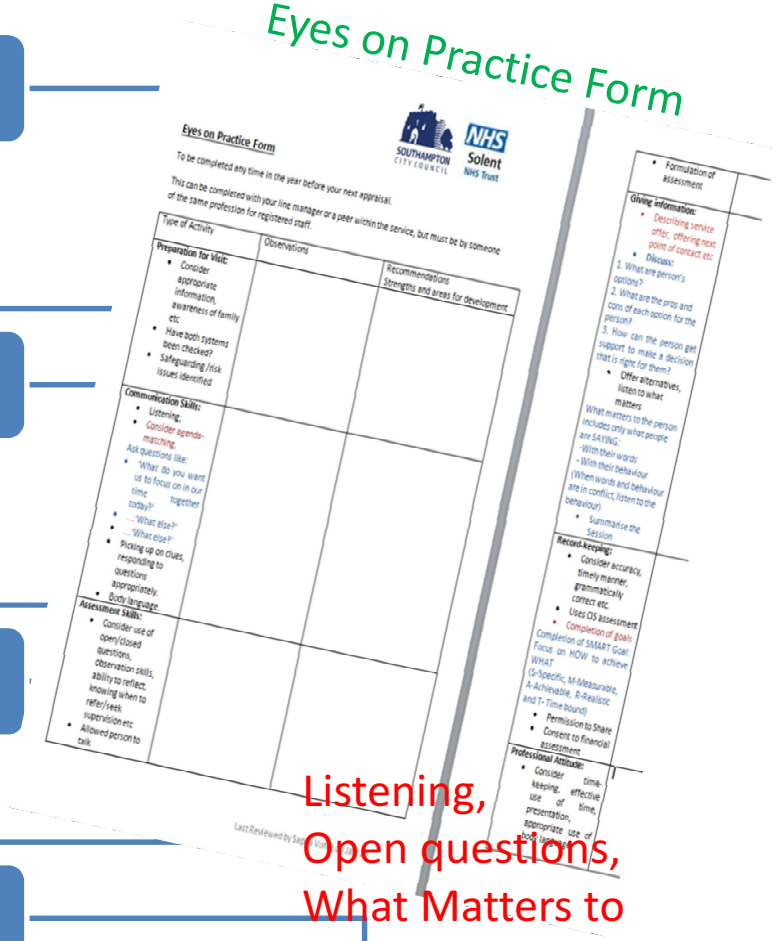
## Shared Decision Making

- Eyes on practice
- Spread awareness

## Social prescribing

- SystmOne Template

## Patient activation and PAM



# Challenges

Change in behaviour – knowing, reflecting to new approach

Staff and services across the health and social care pathway investing in learning, coaching & improvements.

Systems and processes to support personalised care

Southampton Parent Carer Forum

By Vickey Kowal

# Parent Carers report February 2021




# Current difficulties faced by parent-carers

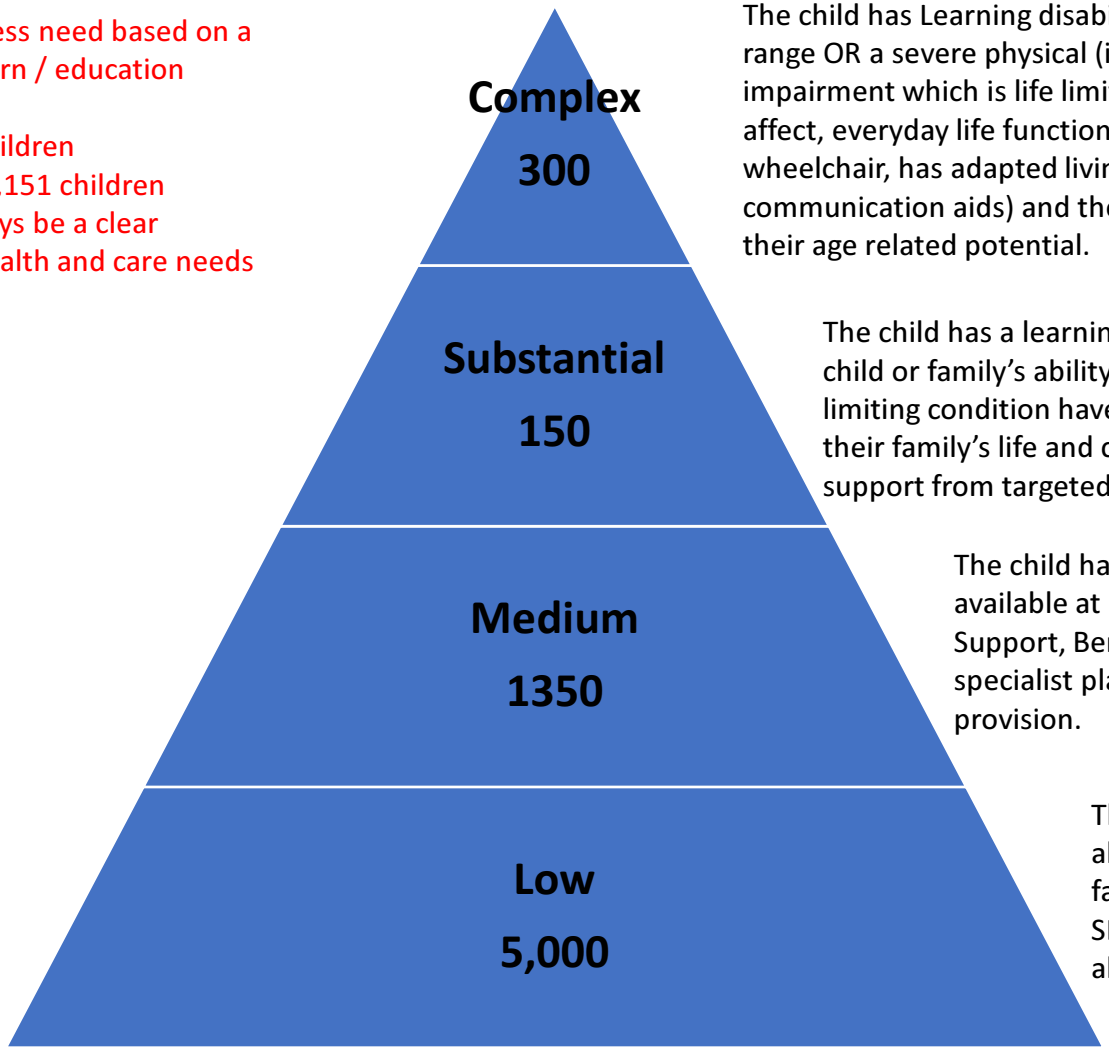
- Lack of easy access to information
- Lack of recognition of needs of parent-carers
- Lack of emotional support
- Lack of practical support
- Financial and housing support
- Breadth of SEND and therefore challenges faced by parent-carers
- Only small percentage of parents able to access carers assessment (statutory requirement) those that do access aren't involved in their own assessment
- Communication
- Parents not seen as experts in their child
- Many families have more than one child with SEND
- For many this is a lifelong role, different needs at different times

# Current model for support

NB. Education assess need based on a child's ability to learn / education outcomes:

- EHCP – 1,411 children
- SEN support – 5,151 children

There will not always be a clear correlation with health and care needs




The child has Learning disabilities within the moderate, severe or profound range OR a severe physical (including visual and hearing) health condition or impairment which is life limiting, or significantly affects, or is predicted to affect, everyday life functioning or a child's access to education (e.g. in a wheelchair, has adapted living, requires total personal care support, requires communication aids) and their ability to achieve outcomes appropriate to their age related potential.

The child has a learning or physical disability that significantly impacts on a child or family's ability to function. The impairment, chronic health or life limiting condition have a substantial impact on the quality of the child and their family's life and child would be unable to achieve outcomes without support from targeted services, coordinated by a lead professional.

The child has additional needs where parents require support above what available at universal level e.g. Special Education Information, Advice and Support, Benefits, carers rights and short breaks from caring through specialist play schemes and clubs, or enhanced/adapted mainstream provision.

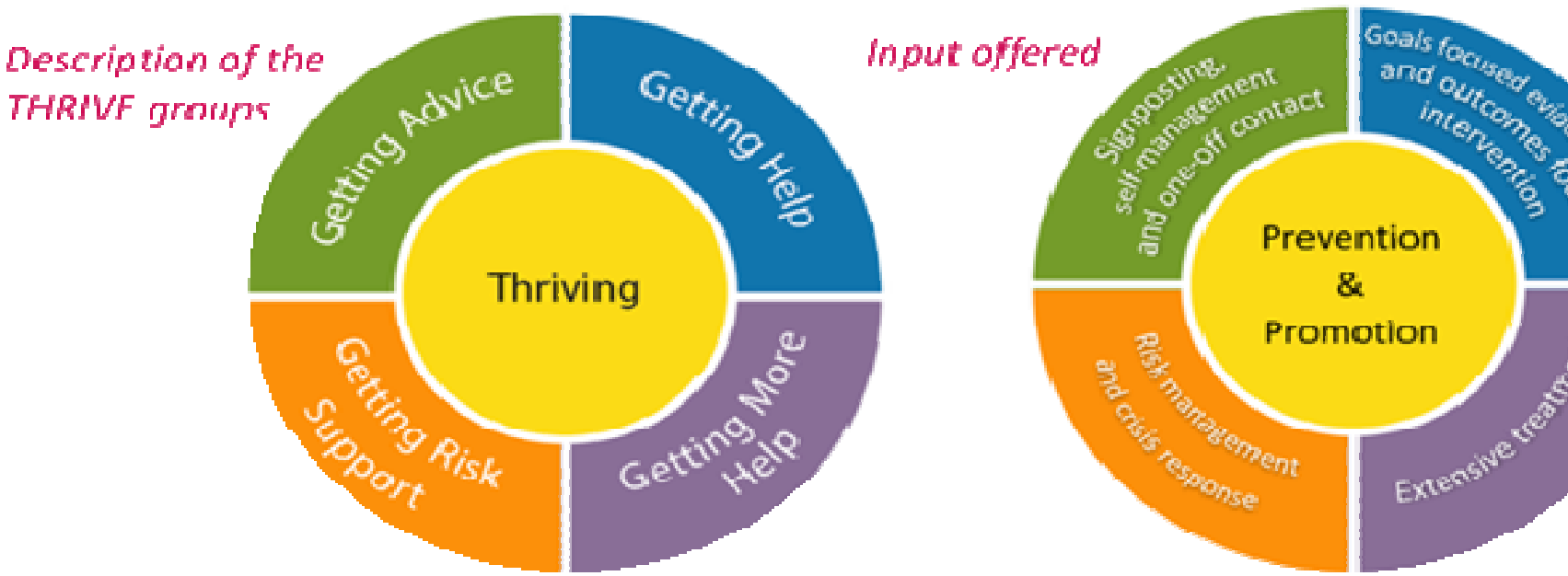
The child has low level additional needs that parents are able to meet through universal services and a network of family and friends. Parents may require signposting to the SEND Local Offer for information, advice and guidance about the universal services available.

# Proposed model

Known as the iThrive model, it is often used by CAMHS services and places families at the center of the model with a needs based approach rather than a service led approach.

Families can move within approach more fluidly








# Recommendations

- Ensure all parent-carers have access to carers assessment that they have an active role in
- Parent-carers treated equitably with other carers whilst recognizing the differences between the two.
- Cultural change from ‘service led and child focused’ to ‘needs led and family focused’
- Increase the number and variety of parent support groups across different areas of SEND and geographical areas of the city
- Support proposed changes to adopt iThrive model
- Provide Parent support for managing children and young people with challenging behaviour
- Ensure timely access to an increased range of parent training and education courses
- Improved communication between professionals/agencies as well as with parents

# What parents say

- ‘On the identification point. Our GP surgery won’t recognise me as a carer because he’s under 18!’
- ‘Took me a while to even understand that parent-carer was a role in its itself, for ages I thought we were talking about parents and/or carers. But once I understood it, I wanted everyone to ‘understand and acknowledge it too. Its real! It does take a while to acknowledge you are a parent-carer - we all thought we were just going to be common or garden parents and then had to adjust to our new lives, roles and responsibilities.
- Covid has meant...if I’m completely honest, more trapped....’
- ‘The only time I get a good night sleep is when my son is in hospital’
- ‘One time we were in hospital a nurse sat down and spent time talking to me about DLA it was only 10 minutes but it made a huge difference’
- ‘Carers in Southampton are brilliant, a lovely organisation and I do feel I could turn to them to ask a direct question. But they don't feel like "my" service after the confusion about Carers assessments I guess I gave up a bit and sorted myself out.’
- ‘I had a breakdown following the fight I had to get suitable special ed place for my boy whilst trying to sustain a teaching career. I have no childcare options for my lad due to his disabilities, no family nearby to take on any caring role and have had to take at least a £20k cut in salary, ending a 20 yr career in teaching.’