# Made in London

New Approaches to Self-Care for Young Adults

## **Executive Summary**

www.londonsenate.nhs.uk/supporting-young-adults-to-self-care



**London Clinical Senate** 

#### MADE in LONDON:

New Approaches to Self-Care for Young Adults

# **Project Goal**

The Made in London project was designed and implemented with the aim of:

Creating a framework for embedding self-care in the commissioning of services for young adults in London.

### **NHS Five Year Forward View**

Initiated by the Patient and Public Voice Group (PPV), part of the London Clinical Senate, the project builds on recommendations in the *NHS England Five Year Forward View* that highlight the importance of supporting people to manage their own health and giving patients greater control of their care.

"Long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather providing single, unconnected 'episodes' of care."

### **Focus on Young Adults**

The Senate identified young adults as a group that was not only underserved but could also, in itself, be an invaluable resource in generating and driving a sustainable programme of work. In this context 'young adults' refers to those between the ages of 16 and 30, and especially young adults with long-term conditions (LTCs), and their carers.

(Feedback from Engagement Workshops) Young Adults: "You can only take responsibility and be in control of your health if there are services to support you."

# **Approach**

The Senate agreed that it could add greatest value in promoting self-care for young adults by:

- // identifying standards of good practice and building an extensive evidence base;
- // engaging young adults in identifying barriers as well as co-production of solutions;
- // developing a self-care framework or methodology that is scaleable and transferable across London; and,
- // highlighting recommendations that can be adopted and applied at a Clinical Commissioning Group (CCG) and Community level to have the greatest positive impact on self-care support.

Recognising that the approach taken to delivering this programme was essential to its success — the programme was designed using the following principles:

- (i) COLLABORATIVE // Bringing young adults/carers, commissioners, and professionals together as equal partners to identify gaps and develop standards for good practice.
- (ii) EVIDENCE-BASED // Developing and promoting evidence-based solutions to support self-care for young adults aged between 16-30.
- (iii) ASSET-BASED // Developing the capacity of young adults to engage effectively in identifying needs, making recommendations, and in planning/development of services.
- (iv) CONTINUOUS & ITERATIVE // Engaging to build and refine sustainable models for local and pan-London commissioning that reflect the needs and aspirations of young adults.

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# Scope of Work

The project was organised into the following four phases:



1// A review of the existing policy and organisational context around self-care support to identify needs and current best practice in programmes for young adults in general, and those with LTCs in particular. This was seen as an essential starting point for the project and would form the foundation on which all the other project phases would be built.

2// Building on the Evidence Review, the Call for Evidence created a space for service providers and community organisations across London to share their experiences of self-care programmes and highlight best practices. As well as identifying key issues, it enabled the creation of a draft framework to be used as the basis for wider engagement.

3// Four community based engagement events were held across London in July 2015 to build on earlier recommendations. Local host organisations were commissioned to undertake the outreach and engagement for these events, including identifying young adults to co-facilitate and lead the main workshops.

4// An additional workshop was organised in October 2015 and served as a platform to collaboratively review the draft recommendations. Young adults, partners, and other stakeholders, were invited to participate and share their thoughts/ideas/suggestions on the proposed next steps, and ensure that the recommendations did, indeed, reflect their earlier feedback.

### Outcomes

Feedback from both the Call for Evidence and the Engagement Workshops supported the House of Care model and the Health Foundation's three-tiered model for transformation, as reflected in the following points:

1/The importance of involving patients and the public in the design and development of services and the production of educational and support tools and systems;

2/ The need for services that are more patient-focused and holistic in their approach to treatment and support;

3/The need for education and training for professionals and patients in order to change the culture of organisations and enable the development and adoption of self-care programmes;

4/ Multi-professional collaborative working that looks beyond the disease/condition and crosses the commissioner/provider/patient boundaries.

[Summary of feedback from the Call for Evidence]

The feedback also reinforced guidance published by NHS England (2015) to support commissioners and practitioners in planning services for people with LTCs >>

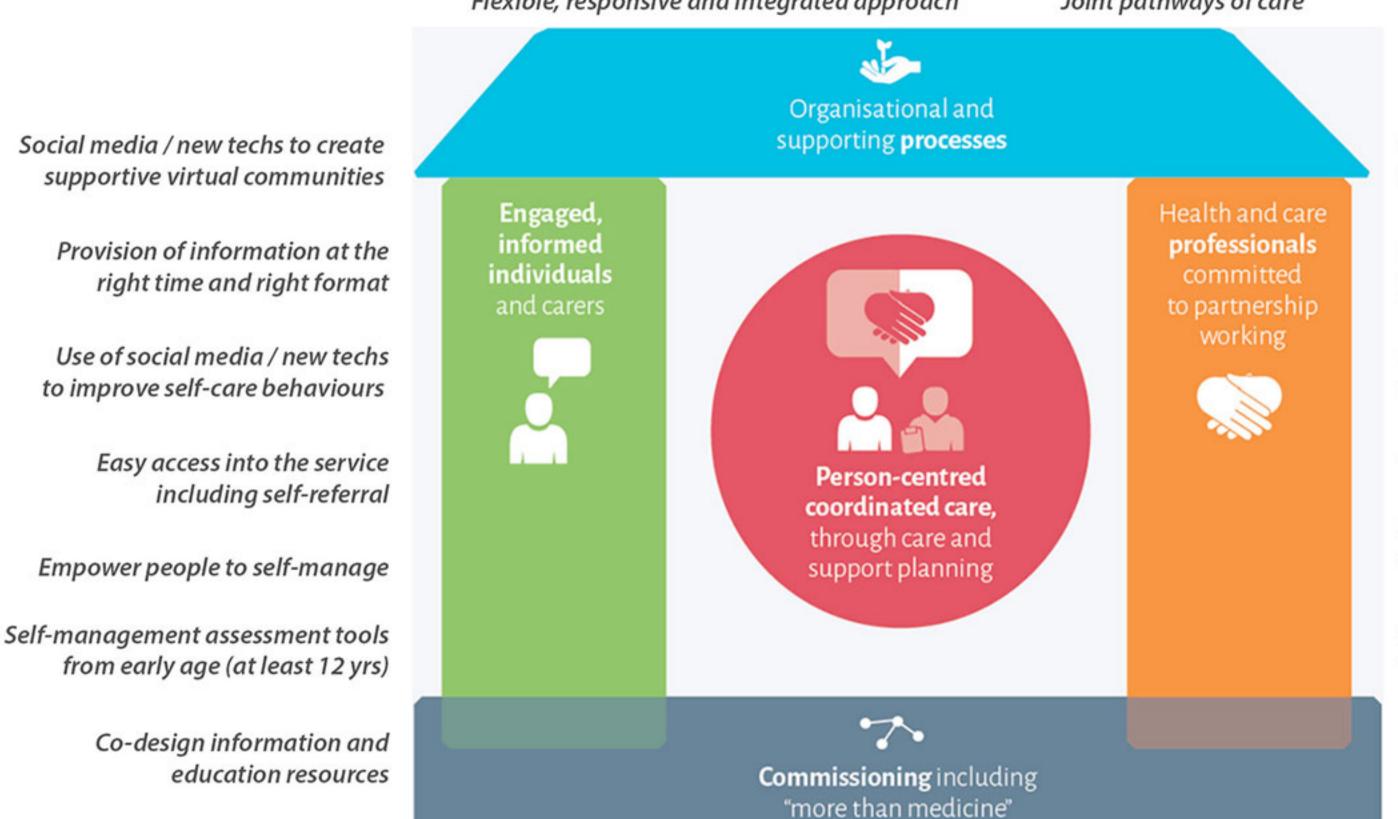
## Feedback/ from Call for Evidence (overlaid on the House of Care)

Funded transition specific therapy posts

Shared facility for health and social care services

Flexible, responsive and integrated approach

Joint pathways of care



Ongoing support through transitional periods

Individualised approach to goal setting and treatment

Holistic framework that encompasses 'health & wellbeing'

Multi-disciplinary engagement

Communication between partners to enable seamless transition of care

Active participation of GPs in care of patients from an early age

Senior buy-in when introducing new models

User involvement in the design of services

Joint commissioning with partner organisations

Fostering partnerships with patients and clinicians

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## Feedback/ from Engagement Workshops

#### **NHS England England Guidance**

to support commissioners and practitioners in planning services for people with LTCs

Ensure that commissioning reflects the needs of individuals, and commission appropriate person-centred services that promote and embed personalised care and support planning;

Promote partnership and collaboration in local health populations to implement a whole system approach;

Commission a range of support services for self-management to supplement traditional services and to ensure a 'more than medicine' approach. This could include structured education programmes, community activities and peer support networks;

Ensure that support is in place to provide people with timely, appropriate and accessible information to enable them to make an informed contribution to discussions regarding their condition, care and support;

Promote the development of clinical environments that encourage shared decision making approaches and ensure support systems are in place to support patients who are less able to embrace this approach;

Promote the development of the workforce to have the skills and competencies to work in this way;

Ensure a robust local measurement system is in place to inform and support improvement.

### Feedback from Made in London Engagement Workshops

Task 4: How do we commission for self-care?

#### // PERSONALISED CARE

Treating people like individuals, rather than a 'condition', and adopting a more holistic view of health & wellbeing that encompasses different dimensions, including mental/emotional, social, as well as clinical

#### // INTEGRATED SERVICES

Creating 'Health Communities' in existing community hubs that are easily accessible, offer flexible timings, and allow seamless referrals e.g. after school clinics or youth centre counselling and support services

#### // STEP-BY-STEP ADVICE

Not just telling people what to do to manage their condition, but explaining and/ or showing how to do it, w/ more information and resources, esp. digital media

#### // PEER SUPPORT NETWORKS

Strengthening existing/creating new support networks that provide ongoing peer support to young adults, and their carers, e.g. community groups, youth centres, mentoring programmes, and peer networks inclu. w/in schools

#### // (I) INFORMATION (Education)

Increasing general awareness about health & wellbeing through e.g. school programmes, peer groups, online and social media, and community groups

#### // (II) INFORMATION (Signposting)

Providing appropriate information about health/social services and where / how to access these in a way that young adults find engaging and accessible

#### // CO-PRODUCTION W/ YOUNG ADULTS

Engaging young adults in shared decion-making, not only in terms of their own health, but also in the design of services

#### // TRAINING GPs and other HCPs

In skills such as communication, active listening, and a better understanding of socio-economic/cultural factors, to allow more open and trusting interactions

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# Feedback/ from Engagement Workshops / Task 2: What do you need to feel supported?

#### BEING GIVEN THE RIGHT INFO & RESOURCES TO MANAGE CONDITION //

HCPs providing a clear understanding of a condition, what to do and why

#### BUILDING RELATIONSHIPS w/ GPs and other HCPs //

Working together to set goals through practical resources (not just talking)

#### RESPECT / TRUST //

Ability to have an open and trusting dialogue with HCPs and creating the conditions that make it safe to share / learn from mistakes, without blame

#### **ACTIVE LISTENING & COMMUNICATION //**

Sense of empathy from HCPs and that someone is actually listening (through attentiveness: greetings, eye contact, body language)

#### TIME //

More time during consultations

#### **ENVIRONMENT //**

Create welcoming and comfortable physical environments

#### KNOWING WHERE TO GET HELP (Signposting) //

Providing information on where to go for additional support

Context

### **Clinical [Professional HCP]**

# Personal [Physical / Emotional]

#### **INFORMATION & RESOURCES //**

Knowing how to make positive changes [to behaviour/attitude], and understanding how to take of yourself - using resources such as mobile apps, digital media, and other creative ways of sharing information

#### RESPECT / TRUST //

Trust in yourself and others, acknowledging personal choices and being able to admit when something didn't work and move on

#### LEARNING TO TAKE RESPONSIBILITY (Resilience) //

Having the confidence in yourself and your ability to self-care, by taking responsibility, and maintaining a strong 'belief in the future'

#### LEARNING from / SUPPORTING OTHERS //

Getting training and ongoing support to mentor other young adults with similar conditions/in similar circumstances, and having this role recognised

#### // SUPPORT NETWORKS (Learning by Example)

Having role models with you to provide support / encouragement, learning from each other's experience and helping others by sharing own personal experience

#### // BUILDING RELATIONSHIPS (w/ Mentors/Teachers/Volunteers/Professionals)

Working in partnership with different people who can help to set goals, monitor a LTC, and understand 'self-care' through practical resources (not just talking)

#### // COMMUNICATION & INFORMATION

Understanding -- breaking down -- what common terminology actually means, e.g. 'responsibility' / 'risk' / 'expectation', and using language more effectively to convey relevant and appropriate information

#### // RESPECT / TRUST

Creating the conditions that make it safe to address the 'what's not talked about space,' e.g. admit mistakes, voice different viewpoints, share other concerns, and learn from experience

#### // KNOWING WHERE TO GET HELP (Signposting)

Providing information on where to go for additional support

### **Community [Psycho-Social]**

Context

### Family / Carers [Personal Support]

#### // RESPECT / TRUST

Parents stepping back and letting young people take the lead

#### // BUILDING CONFIDENCE

(For young adult) Having someone close provide encouragement and support

#### // STRENGTHENING RELATIONSHIPS (w/ Parents & Carers)

Working in partnership with parents and carers to set goals, monitor condition, and learn from experience (including learning from mistakes)

#### // PROVIDING SUPPORT TO PARENTS/CARERS

Providing support (through mentoring) to parents and carers and making sure they have access to the right information and resources, to help them in their role of caring for young adults

### Feedback/ from Engagement Workshops / Task 3: What does Self-Care mean?

The outcomes from the workshops showed that there was no single definition of self-care.

#### Self-care was understood as

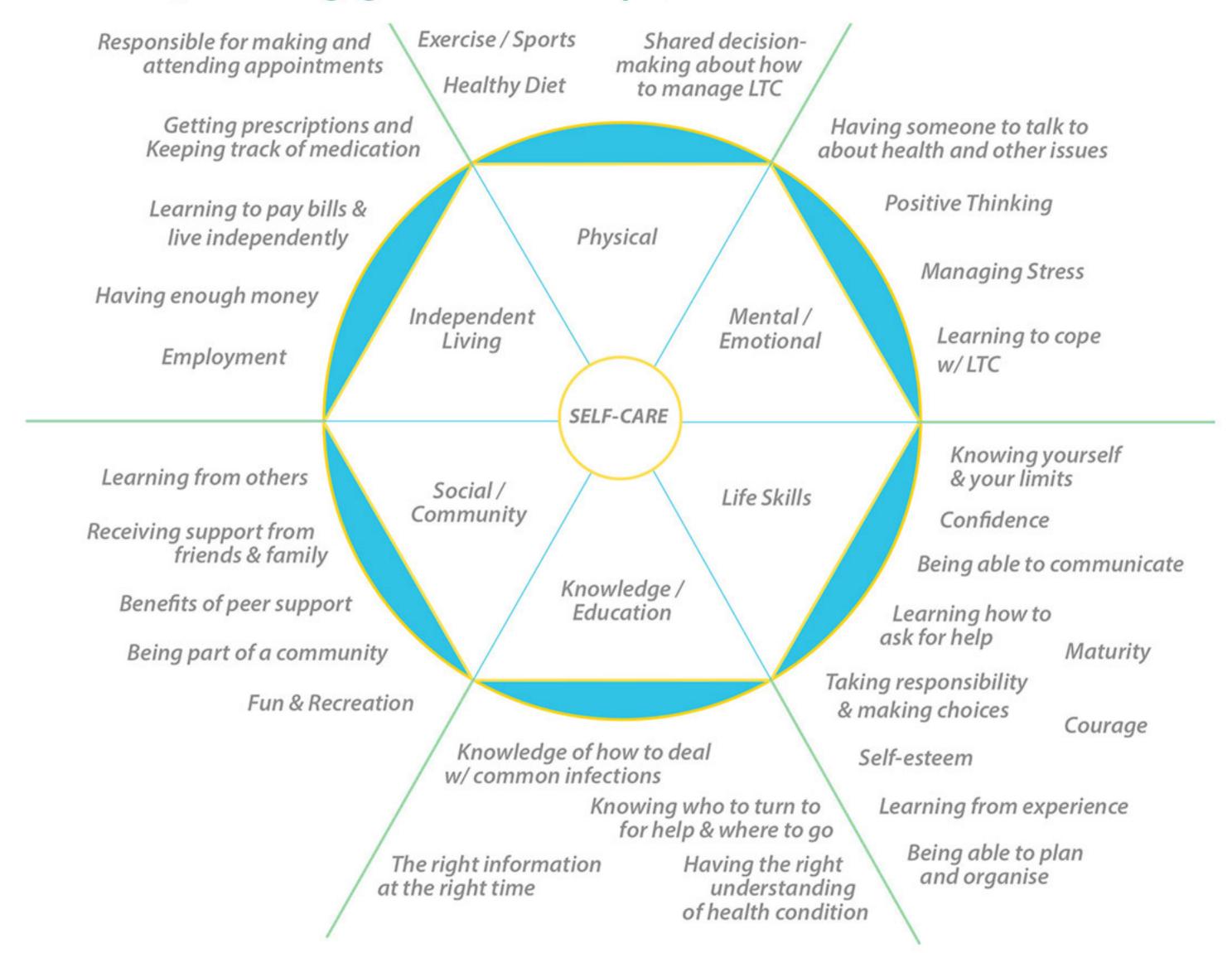
general physical and mental/emotional wellbeing, as well as the ability to deal with day to day life: from positive thinking and recreational activities, to being employed and living independently.

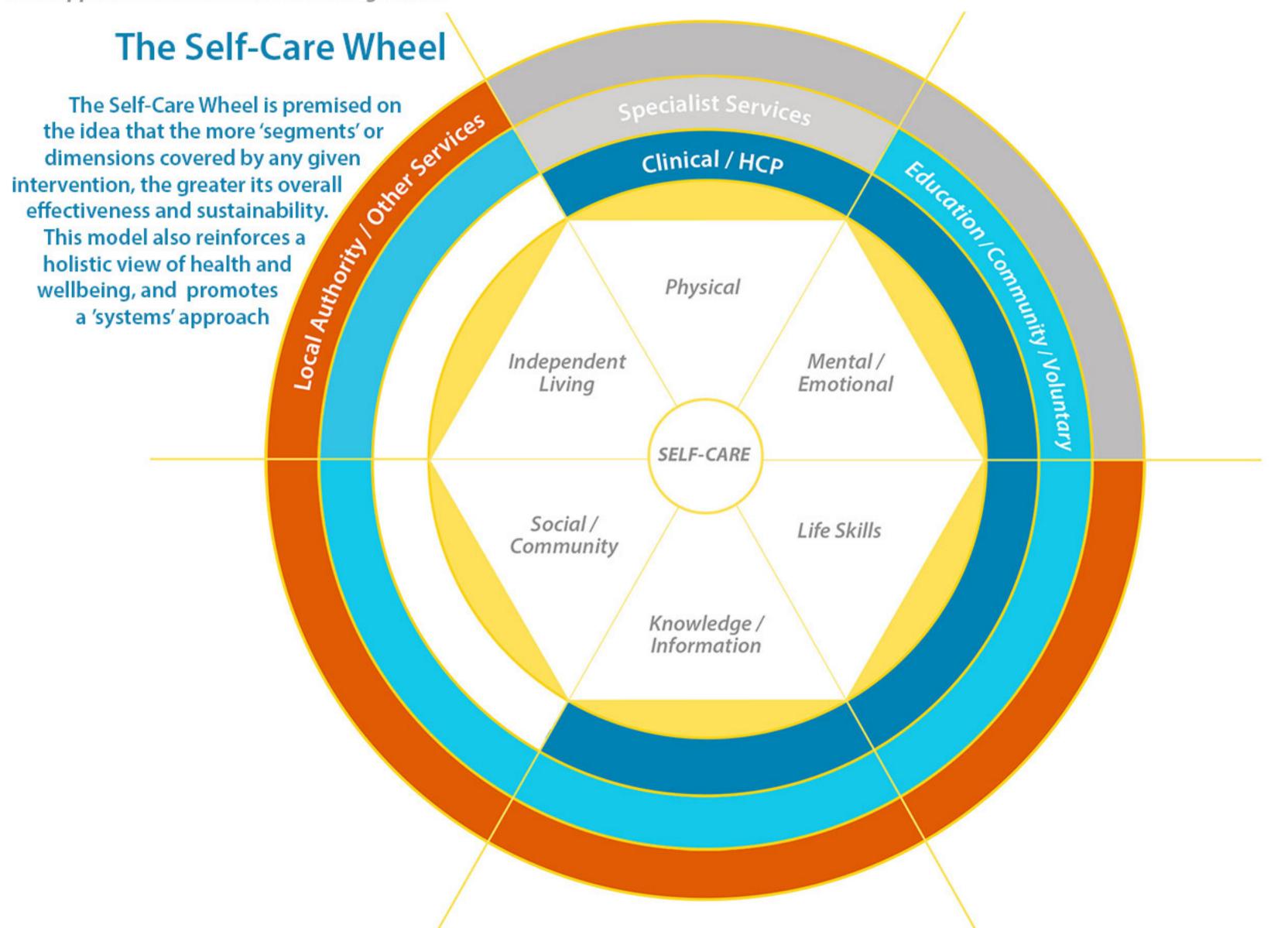
Self-care took on a different meaning for people who had a health condition (such as diabetes). For these individuals, 'self-care' was closely linked to 'self-management' and the ability to integrate the management of their health into daily life.

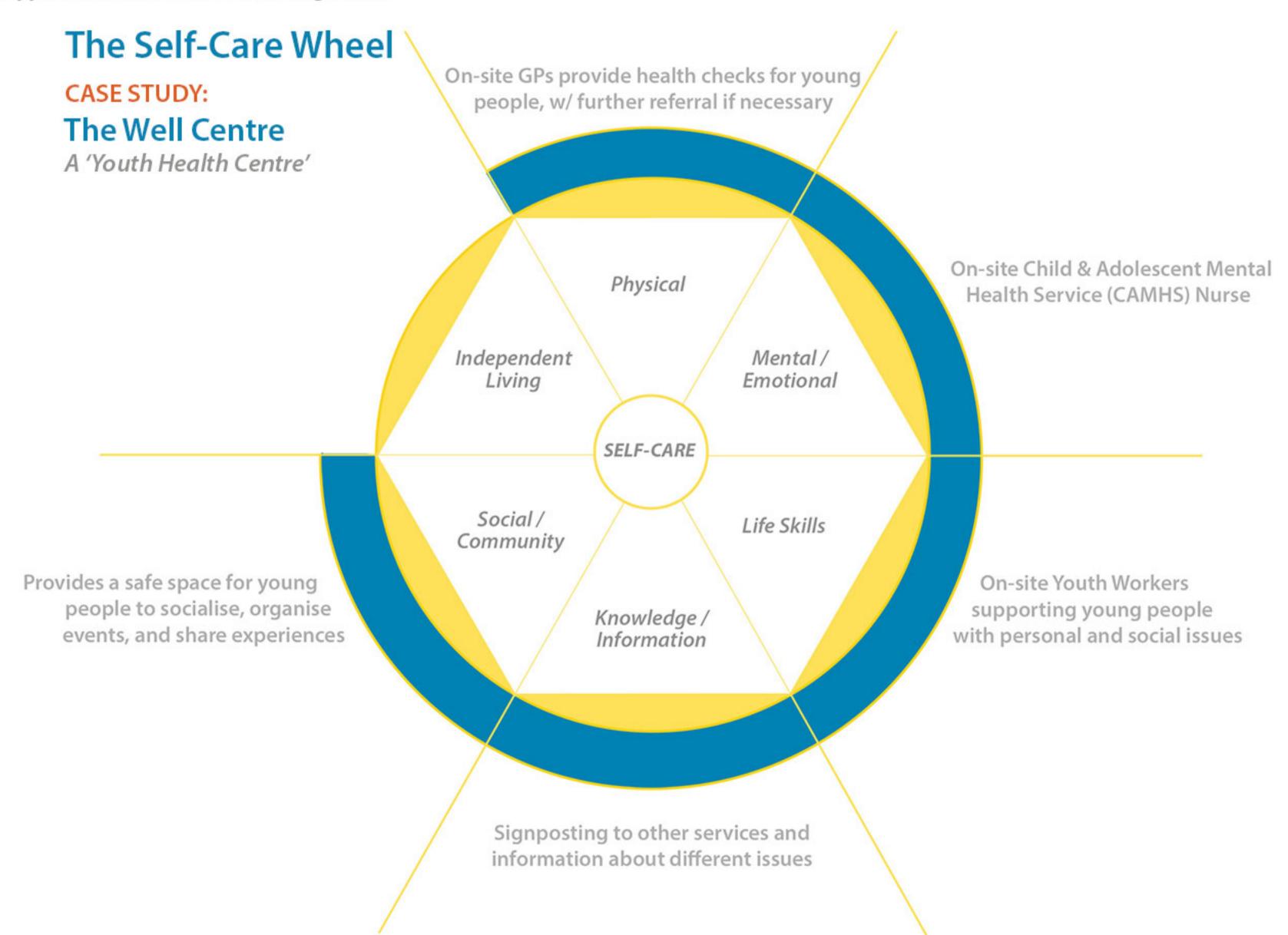
'Self-care', therefore, meant different things to different people, at different times.

The following illustration brings together the different dimensions of 'self-care' high-lighted in the workshops. It also encompasses the different contexts where self-care takes place, including traditional healthcare settings (GP surgeries, clinics, hospitals), schools, colleges, the workplace, community hubs (such as youth centres), and other non-clinical settings.

## Feedback/ from Engagement Workshops / Task 3: What does Self-Care mean?







### **10 Key Points for Commissioners**

#### **APPROACH**

1/ Utitlise a Process-Oriented Approach to commissioning services — one that is:

(i) Evidence-based / (ii) Collaborative

(iii) Asset-based / (iv) Continuous & Iterative

# ENGAGED, INFORMED INDIVIDUALS & CARERS

- 2/ Co-production and Shared Decision-making Involving patients and the public in the design and development of services and the production of educational and support tools and systems.
- 3/ Supporting existing/new peer networks
  Creating 'safe spaces' in the community where
  young adults can share their experiences.

#### PERSON-CENTRED CARE

Delivering services that are more person-centred in their approach to treatment and support, incl:

- 4/ Supporting a holistic view of Health & Wellbeing
- 5/ Personalising Care
- 6/ Creating Welcoming & User-friendly Environments

#### HEALTH & CARE PROFESSIONALS COMMITTED TO PARTNERSHIP WORKING

Education and training for professionals in order to support the development and adoption of self-care programmes, in particular:

- 7/ Embedding a 'Cultural Change' amongst Professionals and within organisations
- 8/ Building Capacity & Training of Frontline Staff

And, multi-professional collaborative working that supports the integration of health and social care, and transcends the commissioner/provider/patient boundaries, through:

9/ Creating 'Health Communities'

# ORGANISATIONAL & SUPPORTING PROCESSES

#### 10/ Enabling 'Systems Thinking'

Create a culture that fosters systems thinking and provides systems leadership to facilitate the creation of multi-disciplinary, integrated frameworks for commissioning services. This includes supporting innovation that actively encourages and evaluates new ideas and projects to build capacity.

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#### **Facilitators**

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