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Well-being and good  
practices for  
independent living



# Intentions:

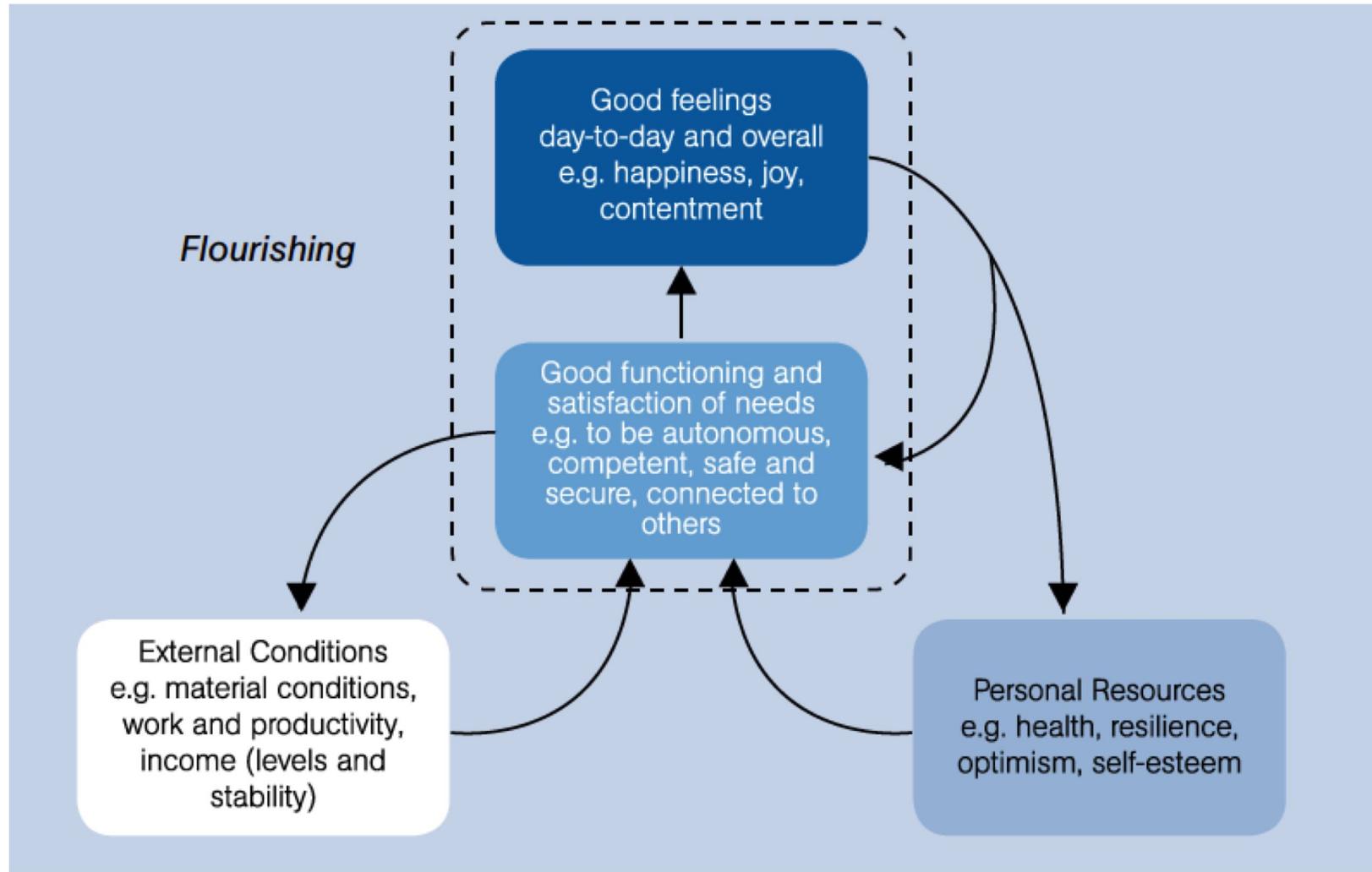
- To explore the idea of wellbeing
- To consider wellbeing from the perspective of people with intellectual (and other disabilities)
- To consider the role of carers, professionals and others in supporting wellbeing
- Explore the capabilities framework as a concept incorporating issues of autonomy and independence
- To have stimulated some ideas for future practice

# Well-being ....

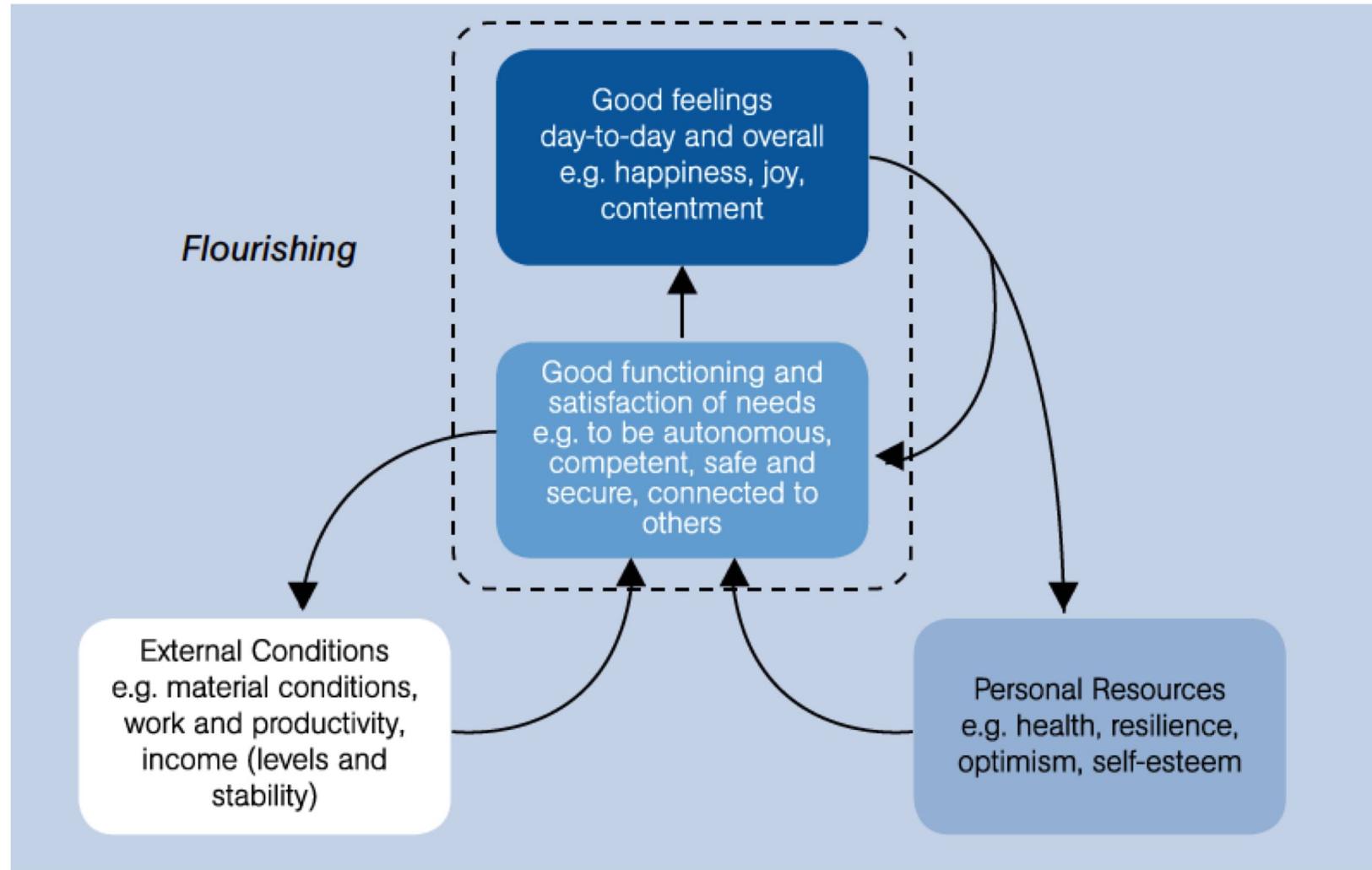
- How people feel
  - *Emotions such as happiness or anxiety*
- How they function on a personal and a social level
  - *Sense of competence or being connected with people around them*
- How they evaluate their lives as a whole
  - *Satisfaction – comparison with ‘best possible life’*

(New Economics Foundation)

# The dynamic model of wellbeing (nef)



How may these factors be compromised for people with intellectual disabilities?



How do people with intellectual disabilities regard wellbeing and quality of life?

Written by >650 young people and adults with learning (intellectual) disabilities in partnership with their peers with a range of physical disabilities, sensory impairments and mental health needs



 Changing Our Lives

Changing Our Lives

Quality of Life

Standards & Toolkit

- Being in control of my life
- My voice
- Staying safe
- Personal care
- Having a full life

- My home
- Employment
- Buying my own support
- Short breaks
- The way people work with me

# Being Belonging Becoming (Wilcock, Bertelli)

B E I N G	<i>Physical Being</i>	<ul style="list-style-type: none"><li>● Being physically able to get around.</li><li>● My nutrition and the food I eat.</li></ul>
	<i>Psychological Being</i>	<ul style="list-style-type: none"><li>● Being free of worry and stress.</li><li>● The mood I am usually in.</li></ul>
	<i>Spiritual Being</i>	<ul style="list-style-type: none"><li>● Having hope for the future.</li><li>● My own ideas of right and wrong.</li></ul>

# Being Belonging Becoming

B E L O N G I N G	<i>Physical Belonging</i>	<ul style="list-style-type: none"><li>● The house or apartment I live in.</li><li>● The neighbourhood I live in.</li></ul>
	<i>Social Belonging</i>	<ul style="list-style-type: none"><li>● Being close to people in my family.</li><li>● Having a spouse or special person.</li></ul>
	<i>Community Belonging</i>	<ul style="list-style-type: none"><li>● Being able to get professional services (medical, social, etc.)</li><li>● Having enough money.</li></ul>

# Being Belonging Becoming

B	<i>Practical Becoming</i>	<ul style="list-style-type: none"><li>● Doing things around my house.</li><li>● Working at a job or going to school.</li></ul>
E		
C	<i>Leisure Becoming</i>	<ul style="list-style-type: none"><li>● Outdoor activities (walks, cycling, etc.)</li><li>● Indoor activities (TV, cycling, etc.)</li></ul>
O		
M		
I	<i>Growth Becoming</i>	<ul style="list-style-type: none"><li>● Improving my physical health and fitness.</li><li>● Being able to cope with changes in my life.</li></ul>
N		
G		

# What is the role of health and social care professionals / supporters ?

- **Health** is a state of complete physical, mental and social well-being and **not** merely the **absence of disease** or infirmity (WHO 1946)
- Health inequalities
- Social determinants of health
- Recovery based models
- Clinical advocacy

# What is the role of health and social care professionals / supporters ?

- A piece of work carried between NHEngland and Pathways Associates (a Community Interest Company involving people with intellectual disabilities, carers, family members)
- With the assistance of Professor Chris Hatton (University of Lancaster)
- Part of evaluation of national learning disability strategy in England

# The capabilities approach: Background

- Comes from work on the economics of low and middle income countries (Amartya Sen; Martha Nussbaum)
  - Importance of moving beyond GDP as an indicator of a country's 'progress'
  - Importance of social justice: judging how well a society treats *all* its citizens
- Increasingly being seen as a framework for understanding inequalities in any society and working towards social justice

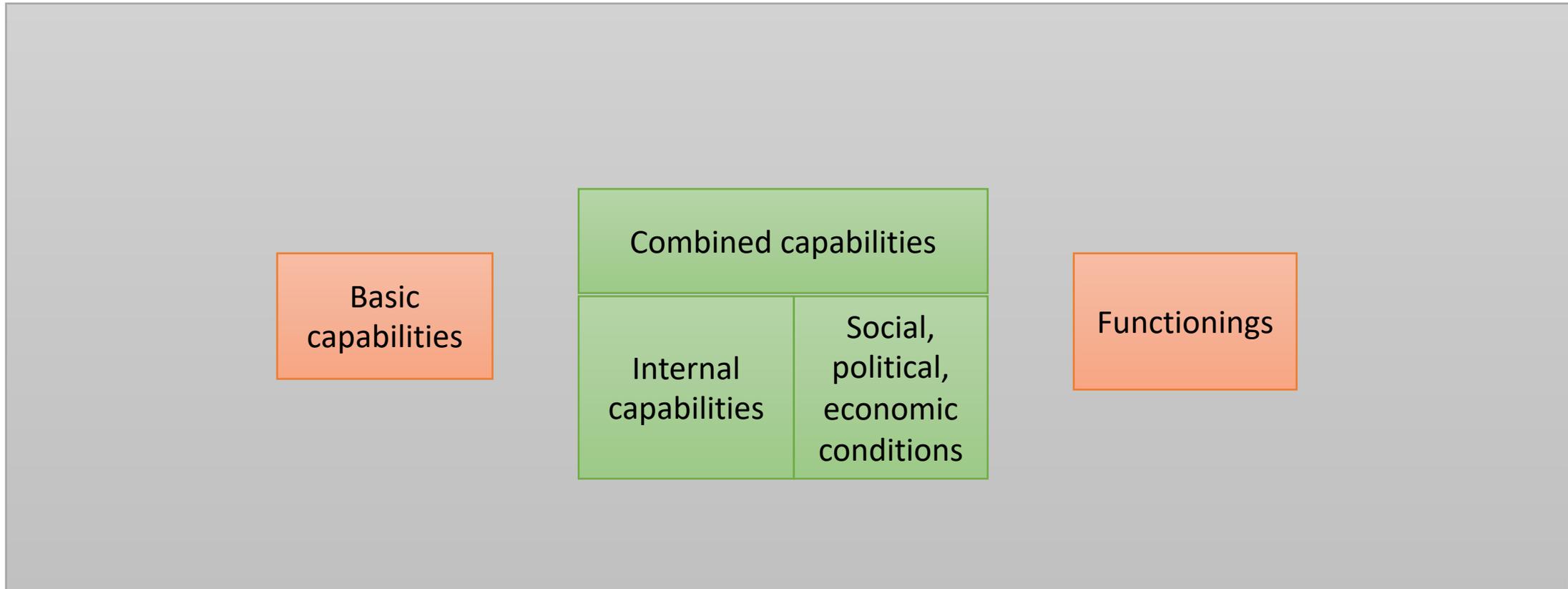
# What are capabilities?

- Capabilities “...are not just abilities residing inside a person but also the freedoms or opportunities created by a combination of personal abilities and the political, social, and economic environment” (Nussbaum, 2011)

# What are capabilities?

- Combined capabilities or substantial freedoms are conceptually distinct from:
  - People's **basic capabilities** (the 'innate equipment' that makes development possible). Because capability frameworks are focused on freedoms for each and every individual, no minimum threshold of basic capabilities is required.
  - **Functioning** (how capabilities are realised in people's lives). The exercise of self-determination via combined capabilities will result in different people choosing different ways of living their lives.

# What are capabilities?



# An example: physical activity & health

Does each and every person with intellectual disabilities have the combined capabilities to exercise self-determination in terms of physical activity?

Has each person has been supported to develop relevant internal capabilities, such as self-efficacy and knowledge about the health consequences of physical (in)activity

Does each person live in environments that actively support and do not hinder the exercise of self-determination in relation to physical activity?

The aim is for people with intellectual disabilities to be able to exercise substantial freedoms in terms of physical activity (levels of physical activity 'functionings' may be different).

A person's basic capabilities will have an influence on how their combined capabilities are to be achieved (e.g. for a person using a wheelchair compared to an ambulant person), but the duty of societies is to achieve combined capabilities for everyone with intellectual disabilities.

# Capabilities for what? Domains

Capability
Life
Health
Bodily integrity
Individual, family and social life
Legal security
Adequate standard of living
Participation, influence & voice
Identity, self-expression & self-respect
Education & learning
Productive & valued activities

# Operationalising the capabilities framework

Capability	Autonomy / choice	Support / enablement	Outcomes (functioning)
Life			
Health			
Bodily integrity			
Individual, family and social life			
Legal security			
Adequate standard of living			
Participation, influence & voice			
Identity, self-expression & self-respect			
Education & learning			
Productive & valued activities			

# Operationalising the capabilities framework

Autonomy	Support / enablement	Outcomes (functioning)
At day program/day activity but would like to go/do something else during the day	Number of community jobs visited	Helps other people
Working a paid job in the community but would like to work somewhere else	Integrated employment a goal in service plan	Total number of months at current community job
Chooses daily schedule	Ever afraid at work or in day program/activity	Of those employed in community continuously employed during the year
Chooses how to spend free time		Of those employed in the community receives benefits
Chose community job		Amount of community gross wages earned during two-week period
Would like to have a paid job in the community		Community hourly wage
		Facility-based hourly wage
		Does volunteer work

## Health and Wellbeing

When we talk about health we mean complete physical, mental and social well-being - not just the absence of disease or illness.

Free text - press Alt+Enter to start a new line within the box

	Quality Indicators	Autonomy Being in charge of own life, and capabilities of the person and engagement with those around them after being in charge of their own life	Support / enablement to include who may be providing support/enablement, and what they would do to make this happen	Evidence of how it is working - what would you see to show this is happening? E.g. goes to college 3 days a week for 2 hours at the class that they asked for.
H1	How is the person enabled to be as healthy as possible through looking after their: <i>Lifestyle</i>			
H2	How is the person enabled to be as healthy as possible through looking after their: <i>Diet</i>			
H3	How is the person enabled to be as healthy as possible through looking after their: <i>Weight</i>			
H4	How is the person enabled to be as healthy as possible through looking after their: <i>Exercise / Fitness</i>			
H5	How is the person enabled to be as healthy as possible through looking after their: <i>Sexual health</i>			

H6	How is the person enabled to be as healthy as possible through looking after their: <i>Substance use (drugs, alcohol, smoking)</i>			
H7	If the person has health conditions how are they supported to be involved in their care and treatment?			
H8	Do family and other supporters understand their health needs?			
H9	If they take medication how are they supported to know about the drugs and their effects?			
H10	How is their treatment reviewed and how often?			
H11	If there are other non-drug treatments (physiotherapy, physical aids such as wheelchairs) are these all readily available and suited to the particular needs of the person?			
H12	Does the person's health / treatment have an impact on the person's ability to live a full and active life?			
H13	How is the person's mental wellbeing supported?			

H14	What activities in their life have a focus on maintaining happiness and fulfilment contributing to good mental health?			
H15	How are others informed and supported to recognise signs of relapse and recovery.			
H16	How does the person communicate discomfort or pain? Are others able to recognise these?			

# Findings

- The capabilities framework was viewed positively
- People could use it
- Gave a clearer indication of the role of supporters / assistants / professionals

# Summary:

- Explore the idea of wellbeing
- Considered wellbeing from the perspective of people with intellectual (and other disabilities)
- Considered the role of carers, professionals and others in supporting wellbeing
- Explored the capabilities framework as a concept incorporating issues of autonomy and independence
- Stimulated some ideas for future practice??

BEACHING HIMSELF  
WAS A QUALITY OF  
LIFE DECISION...



New Economics Foundation Measuring wellbeing – a guide for practitioners (2012)

[https://neweconomics.org/uploads/files/8d92cf44e70b3d16e6\\_rgm6bpd3i.pdf](https://neweconomics.org/uploads/files/8d92cf44e70b3d16e6_rgm6bpd3i.pdf)

Changing our lives : Quality of life – standards and toolkit

<https://www.centreforwelfarereform.org/uploads/attachment/430/quality-of-life-standards-and-toolkit.pdf>

Hatton, C. The capabilities approach as a framework for understanding the lives of people with intellectual disabilities, *Journal of Intellectual Disability Research*, Vol. 56, No. 7-8, 07.2012, p. 816-816.

Bertelli M et al , Individual and family quality of life in intellectual disability: a challenging relationship in :

F. Maggino and G. Nuvolati (eds.), *Quality of life in Italy: Research and Reflections*, Social Indicators Research Series 48, DOI 10.1007/978-94-007-3898-0\_16,