

Children and youth with multiple and complex disabilities:

A review of resources that provide opportunities to activity and participation

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FUB – project report

2008 – stated a need for overviews

- Research and R&D about children and youth with multiple and complex disabilities
- Experiences of “good examples”, “parents tips to other parents” and/or new R&D-results not yet scientifically tested

Nka assignment

To make a review of assistive technology for carer of children and youth with multiple and complex disabilities

Assistive technology – make thoughts go astray to material things and equipment

Assisting resources or
Resources providing opportunities
expands the conceptual meaning

Assisting resources

What resources?

Many things:

- knowledge
- others experiences
- different sources of information
- assistive technology
- adaptations of the physical environment
- and a lot more.....

An overview for whom?

Carer's and children/youth with great variation of needs and circumstances

Families – social, economic and cultural variations

Child/youth – special combinations of disabilities

Every family member/carer and every child/youth with multiple and complex disabilities has their own special needs

Professionals

How to know the needs?

Experiences from work with children, youth and adults with multiple and complex disabilities may provide awareness and understanding

But, only carers who experience everyday life with a person with multiple and complex disabilities can describe their experience and articulate their needs in their special situation

Scoping review

1. Identification of research question
2. Identify relevant literature
3. Selecting studies/literature
4. Chart the material
5. Analyse/compare, sum up and report results

A method used

when the literature is broad and varied

Interviews with parents

Questioning and discussions with parents to children and youth with MCD who I met in my ordinary work

- Informal conversations

”what knowledge do you need” – a big question

difficult to put words on and to choose a need to stop up, think – takes energy, time needs had varied with age, other changes

Literature search

Learning about search paths, librarian, LUB

- Library, databases
- Searches about MCD + profound – a too narrow result
- Disability + severe + special concepts – a wider result that was narrowed
- Searches on references in interesting literature

But also looking for other information sources

- Internet search engines
- Government, authorities
 - Divisions of labour
- Journals, papers, news
 - Social media, blogs
- Ideas from conferences

Plan for the review

Set up, feedback, revision and approval

Version 1 2013 December to Nka

Version 2 2014 January to Nka and carers

Big re-structuring

Version 3 2014 April to Nka and carers

Version 4 2014 August to Nka

Resources providing opportunities

A concept including many things – technical aids for loan or purchase; but also standard equipment that can be used in an “assistive” way; or different interventions or activities.

Also included is human assistance to co-ordinate different services; assist with handling complicated assistive technology and participation in different activities.

Resources providing opportunities facilitate learning, activity, accessibility and participation

Nka – Livets möjligheter, 10-11 March, 2014



Carers comments

- Important that activity is motivating, playful
- Need for double provision of some technical aids
- Transportation of technical aids between home and activities – demands for a big car
- Staff need more knowledge about complicated assistive technology – handling, programming, updating
- Users engaged in development of new equipment
- Human support, assistance
- Siblings and their experiences

Carers comments

- Extremely important that communication is included in the review
- Difficult to find toys and activities engaging the child/youth
- Equipment for environmental control
- Riding, music, new technology
- Happiness is when it is possible to partake in activities that others do (sibling)

Carers concerns

- Difficult text, difficult content
- Evidence, scientific = hard to read
- More useful for professionals
- Little time and energy to access and read information
- Hard to find answers to personal questions
- Trustworthiness, novelty value – new not tested things will be omitted
- Media used for distribution of the review

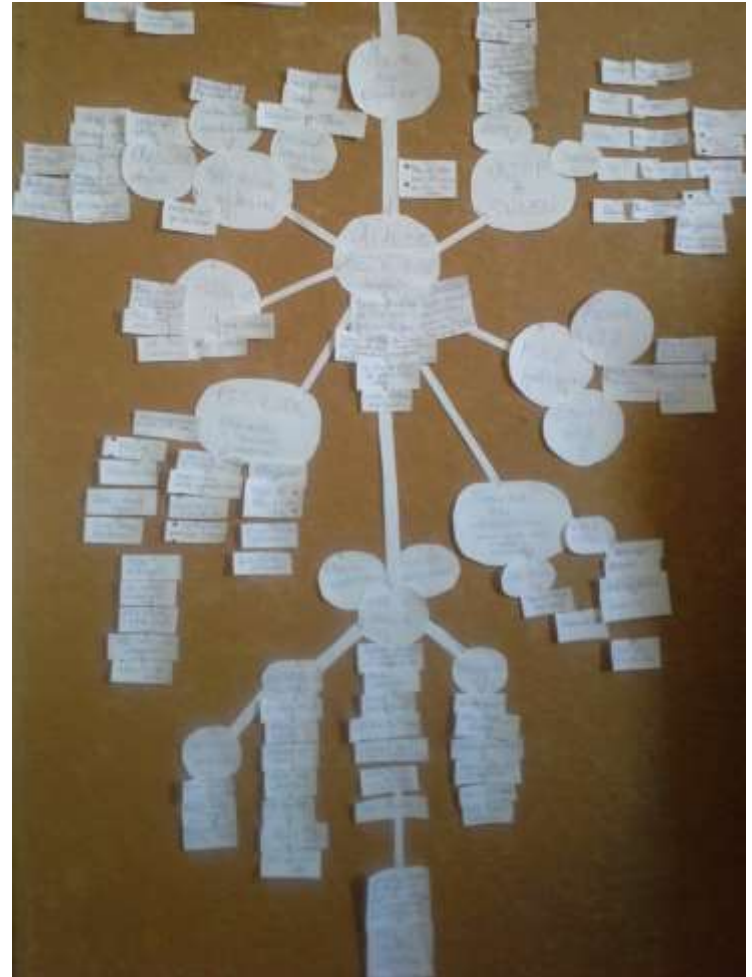
Revision of structure

Second version of the plan was cut up in concepts and indicators, some were omitted and new were added

Concepts and indicators were sorted and laid out in groups, that were pinned up on a big board

Themes and subthemes were grouped and re-grouped and the concepts and indicators were sorted under suiting themes and sub-themes

New structure was written up in the third version of the plan



Final carer comments

”underline the importance of experiences
with ALL senses”

”important to test and do to be able to learn”

”to do a part if not able to do a whole task”

Evidence and/or what is available on the
market?

Accessible and/or useable?

Themes and sub-themes

Three overarching themes

Every theme several sub-themes

Layout

- Title
- Illustrations
- Opening with easy to read text with a bigger font mirroring the content
- Deepened text with references to relevant material
- List of references

Publication

- Book - paperback
- Nka web page
 - downloadable

Theme 1

Activity, participation and learning

To be active and participate with others in different situations is developing

Health and well-being is influenced by which activities we do and how we experiences them

Play and learning is children's doing but also important for everyone over the lifespan

Learning can be supported in different ways but it is important that facilitation is playful and motivating

Theme 2

Personal conditions

Many factors influence a child's possibilities to be active

How the child perceive, interpret and react on impressions

Others being able to stimulate, communicate and respond in ways that the child can recognise and understand

Child's movement ability, possibilities to influence what happens in an activity and have some control of situation

Child's motivation and driving force to be active, willingness to show and express emotions and interests

Conditions in the child's physical and social environment

Theme 3

Resources providing opportunities to activity and participation

Technical aids, knowledge about positioning, personal assistants, physical environment, provision of resources, visions for the future

Useful in everyday life

Works in a predictable way

Accessible when needed

Providing child and family with opportunities to be active and participating in different aspects of life

Thank You!

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