Parents and Professionals: We’re in the same boat, but can we row in the same direction?

Suggestions for improved decision-making about therapies

We are in the same boat because we have the same meaningful goal

The best level of functioning all life long for a child experiencing impairments

But we need to tune us toward this meaningful goal

What do Parents hope for THEIR child?

• MY child to be cured?
• MY child will walk?
• MY child will be happy in life?
• To do my utmost for MY child?
• Whatever my efforts, I don’t want to regret later?

What do Professionals know and want for THIS child?

• THIS child can’t be cured
• THIS child needs to reframe their goals
• THIS child to change and improve their functioning
• THIS child not to have consequences of the disease I know to be incapacitating
• THIS child not undergoing inconvenient interventions...
As a pediatrician involved in Physical Medicine and Rehabilitation what I have learned from books and theory

- Children progress with time whatever our interventions
- A child opens like a fan
- The knowledge of the natural history of the condition
- The challenge in identifying what is responsible for the observed change

As a pediatrician involved in Physical Medicine and Rehabilitation what I am learning from experience and human needs

- This kid is primarily a kid
- “Each family is unique”
- Mandatory early alliance with parents
- Not using the hope to convince
- First, do not harm
- Being humble regarding the effects of our intervention
- Many therapeutic options could lead to the same results
- Importance has to be given to multidisciplinary, including parents

As a pediatrician involved in physical medecine and rehabilitation what I am learning from Evidence in the literature

- Medical knowledge grows every day
- Best scientific evidences are obtained by clinical research
- The rank of scientific evidence according to the strength of their freedom from the various biases that beset medical research.

Research evidence to help inform decisions
• Who is traveling?
• What sort of boat are you using?
• Is there any alternative?
• What’s your destination?

Nautical map charting the journey
- Questions asked by families and/or clinicians.
- Snapshot of published evidence & guidance.
- NHS treatments or Alternative therapies.
Questions to ask

- Who wrote the information
- Look for references or links to a reputable organisation
- Does the site reference sources and statements?
- When was the information created or last updated?
- Is the author selling or promoting a product?
- Is there advertising on the page?
 Researchers can do more to make evidence accessible

A gap between Research and Clinical practices

Number are the examples, in which current medical practices cannot keep pace with the available clinical evidences

- Lack of firmness which will synthesize and make systematic results of the primary scientific researches
- Back to sleep and sudden infant death SYNDROME

- Lack of appropriate frames, systems and strategies which will more efficiently influence professional conducts

Our objectives of building a relationship with a family

"exploring and understanding the lives of children and youths" as a mandatory complement of the knowledge of the underlying pathophysiological mechanisms

- To create a relationship of confidence and inter-personal respect
- To have an idea about their level of knowledge and understanding about the condition to be able to reformulate
- To know more about THIS child and their family expectations
- To adapt therapies and interventions to the context of THIS child everyday life

In 1985, Daniel Stern published the Interpersonal world of the infant in which he developed the concept of “accordage” (tune), a kind of back and forth negotiations and adjustments between the infant and his (human and non human) environment

How can we handle experience reported from peer to peer between families?

- Parents hear and learn a lot from other parents – and that leads to questions for professionals!
- We need to ask:
  - What do the parents understand about what they have heard from another parent about another child?
  - Is the other child, and their treatment, similar to, or different from, the child we are seeing today?
  - Can another child’s experiences be applied to the child we are seeing today?
  - What goals do THESE parents have for their child?
  - Can those goals be addressed in another way?
Our objectives of assessing a child in different aspects of their functioning: To obtain...

- Objective and precise assessment of impairment but, more importantly, of activity limitations and participation restrictions

- A better idea of the trajectory of the condition to be able
  - To define a prognosis with THIS child and family
  - To identify course change in order to inform and if possible take actions to avoid further complications.

- A better definition of attainable goals for THIS child

How do we set goals with the child, the family and team

By Being SMART!

**Specific**

The less specific is a goal, the more difficult it is to measure its success

1. Get Healthy
2. Walk longer
3. Walk daily from home to school

**Measurable**

□ Yes  □ No

[Image of a mathematical visualization and a SMART acronym]

https://www.youtube.com/watch?v=1-SvuFQkJ8
**The Goal Attainment Scaling**

From Kiresuk et Sherman 1968

1 scale for 1 specific goal!

<table>
<thead>
<tr>
<th>Goal attainment scaling</th>
<th>Score</th>
<th>Goal description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worse than start regardless</td>
<td>-2</td>
<td>She cannot walk through the rungs</td>
</tr>
<tr>
<td>Equal to start</td>
<td>-2</td>
<td>She does succeed with help, but she needs to place both feet in the space between all rungs</td>
</tr>
<tr>
<td>Less than expected</td>
<td>-1</td>
<td>She walks with help for at least half of the distance and with alternating feet between the rungs</td>
</tr>
<tr>
<td>Expected equal</td>
<td>0</td>
<td>She walks the whole distance with alternating feet between the rungs with help</td>
</tr>
<tr>
<td>Somewhat more than expected</td>
<td>+1</td>
<td>She walks at least half of the distance without help, but often needs to place a second foot next to the first in order to step over the next rung</td>
</tr>
<tr>
<td>Much more than expected</td>
<td>+2</td>
<td>She walks the whole distance without help and places alternating feet over the next rung</td>
</tr>
</tbody>
</table>

[Steenbeek D, 2005]

**MHAVIE or Assessment of Life Habits (LIFE-H)**

https://nipph.qc.ca/en/

- Based on the perspective of the person, the LIFE-H measures the 
accomplishment of life habits and identifies the disabling situations 
experienced

**Quotation of**
accomplishment level

the types of assistance required

the satisfaction regarding this activity
How can we decide when evidence is lacking? How can we see what is relevant to a specific child/family/issue, as opposed to what ‘works’ for ‘this kind of problem’?

Conclusions

• An alliance between family and professional is mandatory to row in the same direction: the best level of functioning all life long for kids experiencing impairments

• The long-term developmental consequences of a neurological condition should not be speculated upon without consideration of the context, and the focus must shift to a global framework that supports childhood development, with the family at the frontline
Don't miss the Boat!