EVALUATION - COGNITION – MULTIPLE DISABILITIES (ECP)

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Financed by CNSA

Professional partners

Psychologists from all over France having responsibility for assessment

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Research Team
BACKGROUND:

LITERATURE REVIEW ON THE COGNITIVE EVALUATION OF PEOPLE WITH MULTIPLE DISABILITIES

Evolution in the number of publications

Key words: French “polyhandicap + évaluation”, and English “PIMD + assessment”.

Databases: Scopus, Scielo, PsycINFO, CARN, MEDLINE, ERIC and SangePsy.

SOME TOOLS

• The Scale of Assessment for Profoundly and Multiply Disabled Children (Fröhlich, 2013; Fröhlich & Haupt, 1983, 2004; Fröhlich, Haupt, & Marty Bouvard, 1986).

• Development Scale for People with Multiple Disabilities (Fleuron et al., 1997).

• Profil de compétences cognitives des jeunes polyhandicapés (Pereira da Costa et al., 2010).

• Checklist of Child Characteristics (Tadema, Vlaskamp et al., 1993).

• Assessment, Evaluation and Programming System for Infants and Children (Bricker, 1993).

• The Scale of Assessment for Profoundly and Multiply Disabled Children (Fröhlich, 2013; Fröhlich, Haupt, 1983, 2004; Fröhlich, Haupt, & Marty Bouvard, 1986).
CONCLUSIONS

- Only 5 publications analyse the way the previously mentioned tools are used and to what effect.
- The authors most often choose to use more than one tool and to what effect.
- Consensus on the methodologies used and on the choice of the dimensions and variables taken into account in the scales.
- Simon and Lepot-Froment (2007), Boukeras's battery of scales (2008), Boissel and Marmorat (2013), Belzer (2013)...

The result is Skills profile

- Multidimensional and plurifocal assessment.
- Dynamic perspective.
- Direct and indirect observation.

Lack of clarity on sensory, motor and neurological difficulties of the people concerned in the works. Thus the relevance evaluation of the tools and they are difficult to generalise.

CONCLUSIONS

- The authors note the lack of adequate tools and the need to create internationally to foster the circulation of knowledge.
- There is a need to create new tools that could be used.
OBJECTIVES OF THE ECP

• Intended for application to all stages in life
• Analyzing impact within the teams: clinical or use
• Testing interest during the period of admission
• Multiple Disability After 6 Years of Using P2CJP
• Evaluation of a scale relating to unhappiness versus well-being,
  (research purposes)
• Construction of profiles in computerized format (for both clinical and
  intended for application to all stages in life)
• Revision of items P2CJP following feedback from users

DISABILITY AFTER 6 YEARS OF USING P2CJP

OBJECTIVES OF THE ECP

• Support to the understanding manifestation of mental suffering
  oriented intervention.
• Evaluation of the effects of an educational and or rehabilitation
  elaboration of a personalized project,
• A diagnosis with a view to an orientation
• Provide help in reforming:

OBJECTIVES

• Be integrated in the person’s cognitive psychological assessment
  • Be open to use by teams of professionals with families as the mediators for crossed observation at all stages in care
  • Allow for longitudinal follow-up

• Identify:
  1) competences and deficiencies,
  2) the sensorial and motor channels that can most readily be modelled,
  3) the child’s modes of expression and/or responsiveness,
  4) signs of mental suffering

• Be integrated in the person’s cognitive psychological assessment

CHOICES MADE

• Crossed observations: direct / indirect / setting the context
• Dynamic evaluation: test and re-test to contrast the person to herself over time.
• Encouraging discussions and exchanges
• Understanding the differences without seeking a mean or a “norm”.

Competences profile:

Psychologists
Educational professionals and/or carers
Close friends, family

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The form of the tool: 

- Scoring grid: Frequency as a measurement variable reviewed
- Evaluation of levels of acquisition (acquired or being acquired)
- Assessment time
  - Rather long, but can be done in a number of sessions.

Assessment with a group of professionals

Assessment that can be accompanied by the psychologist for the parents

Self-administered assessment

HOW USE IT

COTATION
1) An information form about

2) 3 scales

2) The condition of undergo scales

1) The person PMD

This scale is divided into 4 sub scales.

- His mood and emotional state
- Communicating and expressing
- Behaving
- Being

Evaluation of the natural state of the person with multiple disabilities, allowing to know his/her way of:

SCALE 1 - RESPONSIVENESS SCALE
Cotation

For each statement, tick the box corresponding to your observations during the last 6 months:

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. « Imp. »</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. « NSPP »</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. « 1 »</td>
<td></td>
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</tr>
</tbody>
</table>

COMMENTAIRES :
- « Imp. » : impossibility for the person, because of its deficiencies.
- « NSPP » : the assessor does not know enough the person or he has never seen the person confronted with this situation.
- « 1 » : this behavior was not observed because of the cognitive deficiencies confronted with this situation.

Table 1: Scale of Reactivity. When the behavior was not observed, then 3 options, then 2 options.
<table>
<thead>
<tr>
<th>Commentaires</th>
<th>1. Émissions sonores, cris, vocalises, toux, gémissements…</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Prononce de manière distincte des voyelles, des syllabes…</td>
</tr>
<tr>
<td></td>
<td>3. Prononce des mots</td>
</tr>
<tr>
<td></td>
<td>4. Peut reproduire un son, chantonner…</td>
</tr>
<tr>
<td></td>
<td>5. Arythmies de la respiration (blocages du souffle ou hyperventilations…</td>
</tr>
<tr>
<td></td>
<td>6. Bavages, salivations</td>
</tr>
<tr>
<td></td>
<td>7. Vomissements, régurgitations</td>
</tr>
</tbody>
</table>

**SCALE 2 – COGNITIVE SKILLS PROFILE**

Organized in:

- 8 sub-scales for a person of 13 or more years old.
- 9 sub-scales for a person of 13 or more years old.

For certain sub-scales, there is:

- Items of "base"("basis")
- Items of "Complementary" items to refine the evaluation of capacities. They are not integrated into the calculation of the total score and thus into the construction of the profile.
2.1. CAPACITÉS SENSORIELLES (Il s'agit des réactions orientées ou intentionnelles et non de réactions spontanées)

<table>
<thead>
<tr>
<th>Comptes</th>
<th>Imp.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Sous-section de base**

**Raisons**

- **Étapes**
  - Étapes 1
  - Étapes 2

**informations**

- Informations 1
- Informations 2

**Questions complémentaires**

- Questions 1
- Questions 2

**Commentaires**

- Commentaires 1
- Commentaires 2

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**Tableau**

<table>
<thead>
<tr>
<th>Comptes</th>
<th>Imp.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Tableau de données**

<table>
<thead>
<tr>
<th>Comptes</th>
<th>Imp.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Diagramme**

- Diagramme 1
- Diagramme 2

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**Graphique**

- Graphique 1
- Graphique 2

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**Nouvelles informations**

- Informations nouvelles 1
- Informations nouvelles 2

---

**Résultats**

- Résultats 1
- Résultats 2

---

**Conclusion**

- Conclusion 1
- Conclusion 2
This scale takes back the items of the scale 1 to highlight the possible difference with the usual state. It is then a help to seize better the sense of the psychic suffering expressed for a subject.

In a psychological assessment this scale can be used:

- In a psychological assessment.

<table>
<thead>
<tr>
<th>Traitement</th>
<th>Jamais observé</th>
<th>Souvent observé</th>
<th>Systématiquement observé</th>
<th>NSPP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
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<tr>
<td>3</td>
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<tr>
<td>4</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
### During the last two months has the person lived one of the following situations?

**1.** Perte d'une ou plusieurs compétences

**2.** Acquisition d'une ou plusieurs nouvelles compétences

**3.** Aggravation de son état de santé

**4.** Amélioration de son état de santé

**5.** Changements familiaux vécus de manière négative (séparation, éloignement, décès d'un proche, …)

**6.** Changements familiaux vécus de manière positive (naissance, mariage, fêtes, …)

**7.** Changements dans l'accompagnement et/ou les soins

**8.** Souffrance, maladie, accident d'un proche

**9.** Séparation d'avec un lieu ou une personne affectionné(e)

**Autre(s) événement(s) à préciser**: Durant ces 2 derniers mois, la personne a-

- Oui
- Non
- NSPP : l'observateur ne peut pas se prononcer.

### Impression

**Jam./NA**

**Rare/EA**

**Souv./EA**

**Syst./A**

### Commentaires

**AU COURS DES 2 DERNIERS MOIS, LA PERSONNE…**

1. a plutôt été joyeuse, gaie, a montré facilement du plaisir, a été souriante.
2. a plutôt été sereine/tranquille/paisible
3. s'est montrée plutôt sociable
4. s'est montrée plutôt solitaire
5. s'est montrée angoissée/stressée (s'est montrée facilement anxieuse)
6. s'est montrée très fatigable
7. s'est montrée essentiellement triste
8. s'est montrée peureuse/craintive (facilement effrayée)
9. s'est mise facilement en colère
2 post-doctorands recruited

2 partner parents and professional associations.

A group of 77 psychologists and institutions mobilised, working in a variety of institutions in France.

Research 2014-2017

Organisation of

Profiles
**VALIDATION PROCESS** (METTRE UN CAS AVEC LES SOMMES)

<table>
<thead>
<tr>
<th>Year (7-8)</th>
<th>16</th>
<th>12</th>
<th>18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult (18-65 years)</td>
<td>20</td>
<td>33</td>
<td>3</td>
</tr>
<tr>
<td>Adolescent (17-18 years)</td>
<td>22</td>
<td>22</td>
<td>3</td>
</tr>
<tr>
<td>Children (0-13 years)</td>
<td>22</td>
<td>21</td>
<td>2</td>
</tr>
</tbody>
</table>

**Dates for assessment**
- March to June 2015
- October to December 2015
- December to April 2017

<table>
<thead>
<tr>
<th>Psychologists accepting the research</th>
<th>160</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologists involved</td>
<td>103</td>
</tr>
<tr>
<td>Research records</td>
<td>160</td>
</tr>
</tbody>
</table>

**Children (0-13 years)**
- 45 cases
- 3 cases
- 22 cases

**Adolescents (13 to 18 years)**
- 56 cases
- 3 cases
- 33 cases

**Adults (+18 years)**
- 72 cases
- 12 cases
- 44 cases

**Number of cases**
- 3 scales filled in per case
- 175 cases
- 71 cases
- 71 cases

<table>
<thead>
<tr>
<th>Children (0-13 years)</th>
<th>22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescents (13-18 years)</td>
<td>33</td>
</tr>
<tr>
<td>Adults (+18 years)</td>
<td>44</td>
</tr>
</tbody>
</table>

**Method**

Churchill paradigm (1979)
### Quantitative Validation

**Statistical Validation**

- Analytical of items: Internal consistency tests (correlations)
- Cronbach's alphas: Internal consistency of scales
- Factor analyses: Unidimensional nature of scales
- Verify the unidimensionality of the scales
- Descriptive statistics: (average, standard deviation, asymmetry)

**Cronbach's alphas for the entire sample (n=86)**

<table>
<thead>
<tr>
<th>Sensory capacities</th>
<th>Attentional abilities</th>
<th>Learning abilities</th>
<th>Spatio-temporal skills</th>
<th>Reasoning</th>
<th>Communication skills</th>
<th>Memory</th>
<th>Additional abilities</th>
<th>Socio-emotional competences</th>
<th>Psychologists</th>
<th>Professionals</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.90</td>
<td>0.95</td>
<td>0.92</td>
<td>0.88</td>
<td>0.86</td>
<td>0.70</td>
<td>0.75</td>
<td>0.74</td>
<td>0.90</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.96</td>
<td>0.96</td>
<td>0.92</td>
<td>0.86</td>
<td>0.75</td>
<td>0.73</td>
<td>0.74</td>
<td>0.73</td>
<td>0.89</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cronbach's alphas satisfactory
**QUALITATIVE EVALUATION**

- 5 collaborative working meetings (researchers – psychologists – professionals – parents) throughout the research.
- Free comments in writing from psychologists, following each version’s practical assessment.
- 5 semi-directive interviews

**WORKING GROUP ASSESSMENT**

<table>
<thead>
<tr>
<th>Version</th>
<th>Psychologists</th>
<th>Professionals</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>V1: Paris</td>
<td>36 psychologists</td>
<td>1 professional</td>
<td>1 parent</td>
</tr>
<tr>
<td>V2: Paris</td>
<td>20 psychologists</td>
<td>2 professionals</td>
<td></td>
</tr>
<tr>
<td>V3: March 2017</td>
<td>5 psychologists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>V2: March 2016</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>V1: September 2015</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Objectives:** Collaborative work between researchers and professionals.
QUALITATIVE FEEDBACK

Evaluation of certain aspects of skills that may be overlooked / not considered without being reminded of through the items on the scale.

Focus on diversified skills but also identification of difficulties.

Mediator for the relation.

Difficulties of psychologists in institutions, with have lack of time, little knowledge of these people.

Rewrite several items

Creation of new items „ex nihilo“.

Eliminate some items considered not informative

Consequently, we have modified the items

We have determined the different dimensions to be evaluated.

In collaboration with the Practitioners users of P2CP
Proposal for a computerised version

Facilitation to enter the results in the computerised file of the person with PIMD.

Tool for research that will allow data to be collected using IT resources.

Possibility of regular revision while also allowing for computer-mediated feedback on practice.

METHODOLOGICAL PERSPECTIVES

Importance and advantage of combining

- Quantitative validation by collecting and analysing feedback from all users (parents, families and professionals).
- Qualitative validation by collecting and analysing feedback from all users (parents, families and professionals).

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BIBLIOGRAPHY


