

RESEARCH TEAM

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Psychologists from all over France having responsibility for assessment

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EVALUATION - COGNITION - MULTIPLE DISABILITIES (ECP)

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Speaker: Pr. Régine Scelles, Director of Research.
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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 Serein, 1997).
- *Profil de compétences cognitives des jeunes polyhandicapés* (Pereira Da Costa et Scelles, 2010).
- *Assessment, Evaluation and Programming System for Infants and Children* tool (Bricker, 1993).
- *The Checklist of Child Characteristics*, (Tadema, Vlaskamp et Ruijsenaars, 2005)

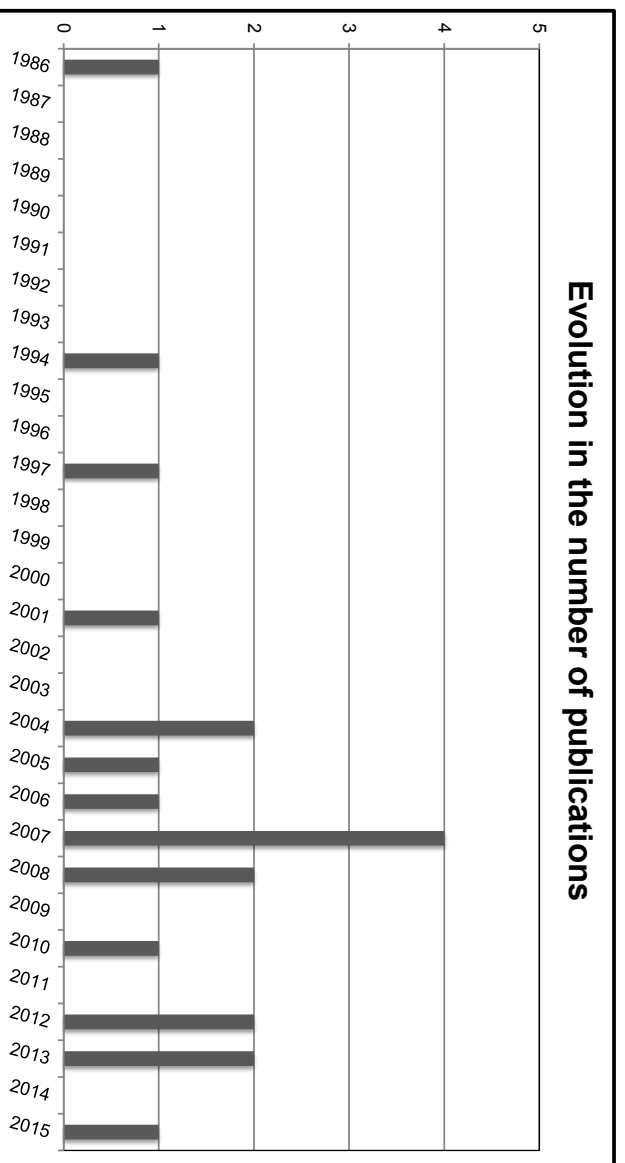
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BACKGROUND:

LITERATURE REVIEW ON THE COGNITIVE EVALUATION OF PEOPLE WITH MULTIPLE DISABILITIES

Databases: ScienceDirect, PsycINFO, CAIRN, MEDLINE, ERIC and SantéPsy

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



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CONCLUSIONS

- 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**
- There is a need to create new tools that could be used internationally to foster the circulation of knowledge
- The authors note the lack of adequate tools and the need to create standardised protocols that would allow for an evaluation of the cognitive skills of people with multiple disabilities.

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CONCLUSIONS

- Only 5 publications analyse the way the previously mentioned tools are used and to what effect.
- The authors most often chose to use more than one tools
Simon and Lepot-Froment (2007), Boukeras's battery of scales (2008) Boissel and Marmorat (2013) Belzer (2013)...
- Consensus on the methodologies used and on the choice of the dimensions and variables taken into account in the scales:
 - direct and indirect observation
 - dynamic perspective
 - multidimensional and plurifocal assessment.
- The result is Skills profile

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OBJECTIVES OF THE ECP

- provide help in refining:
 - a diagnosis with a view to an orientation,
 - the elaboration of a personalised project,
 - evaluation of the effects of an educational and or rehabilitation oriented intervention.
- Support to the understanding manifestation of mental suffering

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OBJECTIFS : ECP EVALUATION - COGNITION – MULTIPLE DISABILITY AFTER 6 YEARS OF USING P2CJP

- Revision of items P2CJP following feedback from users
- Construction of profiles in computerised format (for both clinical and research purposes)
- Addition of a scale relating to unhappiness versus well-being, affective and emotional life
- Testing interest during the period of admission
- Analysing impact within the teams: clinic of use
- intended for application to all stages in life

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CHOICES MADE

- Crossed observations: direct / indirect / setting the context.
 - Close friends, family
 - Educational professionals and/or carers
 - Psychologists
- Dynamic evaluation: test and re-test to contrast the person to herself over time.
- Competences profile:
 - Understand the differences without seeking a mean or a “norm”.
 - Encouraging discussions and exchanges

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OBJECTIVES

- 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 open to use by teams of professionals, with families as the mediators for crossed observation at all stages in care
- Be integrated in the person's cognitive psychological assessment

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HOW USE IT

- Self-administered assessment
- Assessment that can be accompanied by the psychologist for the parents
- Assessment with a group of professionals

COTATION

- 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.

SCALE 1 – RESPONSIVENESS SCALE

- Evaluation of the natural state of the person with multiple disabilities, allowing to know his/her way of:
 - being
 - behaving
 - Communicating and expressing
 - His mood and emotional state

This scale is divided into 4 sub scales.

STRUCTURE OF THE TOOL

1) An information form about

- 1) The person PMD**
- 2) The condition of undergo scales**

2) 3 scales

SCALE 1 AND 2

When the behavior was not observed, then 3 options:

1/ « Imp. » (impossible) : "Imp. " impossibility for the person, because of its deficiencies, to make what evokes the item.

2/ « NSPP » (Ne Se Prononce Pas) The assessor does not know enough the person or he has never seen the person confronted with this situation

3/ not « 1 » : This behavior was not observed because of the cognitive deficiencies

COTATION

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

COMPORTEMENT :					
Imp.	NSPP	Never observe and/or Not acquired	Rarely observed And or Being acquired	Often observed And or Being acquired	Systematically observed and or Totally acquired
		1	2	3	4

Table 1: Scale of reactivity.

SCALE 2 – COGNITIVE SKILLS PROFILE (PCC)

Organized in :

- 8 sub-scales for the children,
- 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

	1. ETAT HABITUEL DES MANIFESTATIONS OROPHARYNGEES	Imp.	1. NSPP		2. P. Prév./EA		3. P. Sév./EA		4. Syst./A	Commentaires
			1	2	1	2	1	2		
1	Emissions sonores, cris, vocalises, toux, gémissements, ...		1	2	3	4				
2	Prononce de manière distincte des voyelles, des syllabes		1	2	3	4				
3	Prononce des mots		1	2	3	4				
4	Peut reproduire un son, chanter,...		1	2	3	4				
5	Arthmies de la respiration (blocages du souffle ou hyperventilations...)		1	2	3	4				
6	Bavages, salivations		1	2	3	4				
7	Vomissements, régurgitations		1	2	3	4				

2.5 - RAISONNEMENT

Sous-échelle de base						
33	Utilise un objet intermédiaire pour atteindre un but ou solliciter une aide pour le faire (prendre un bâton pour approcher un objet convoité...)	1	2	3	4	
34	Comprend une relation de cause à effet (sait que lorsque l'on appuie sur l'interrupteur, la lumière s'allume...)	1	2	3	4	
35	Dans une situation donnée, un geste, une action lui permet d'anticiper ce qui va suivre (sait que l'on sort quand son manteau lui est présenté ; se calme en arrivant dans la cuisine quand elle a faim...)	1	2	3	4	
36	Recherche par l'action ou le regard un objet que l'on veut de cacher ou qui vient de disparaître (le grand bâton du petit bâton...)	1	2	3	4	
37	Distingue les grandeurs (le grand bâton et disparait de sa vue...)	1	2	3	4	
38	Fait preuve d'humour (essaye de faire rire les autres...)	1	2	3	4	
39	Comprend quelqu'un qui fait de l'humour (réagit à l'humour d'un autre...)	1	2	3	4	
Sous-échelle complémentaire						
	Sait reconnaître si des éléments concrets sont de la même famille (catégorise) (aliments, animaux, couleurs...)	1	2	3	4	
	Repère la présence d'un élément inhabituel dans une situation familière (voit qu'un objet n'est pas à sa place, qu'une personne n'est pas présente comme prévu...)	1	2	3	4	
	Distingue les quantités (manifeste une préférence pour avoir un paquet qui contient la plus grande quantité de choses qu'elle aime (chocolat ou friandise...))	1	2	3	4	

Tableau 2: Composition de l'échelle 2: Profil des compétences cognitives.

	Imp.	NSPP	Jant./NA	Pare/EA	Souv./EA	4. Syst./A	Commentaires
2.1. CAPACITES SENSORIELLES (Il s'agit des réactions orientées ou intentionnelles et non de réactions « réflexes »)							
Sous-échelle de base							
1	Réagit à une stimulation sonore (parole, musique, chant des oiseaux...)	1	2	3	4		
2	Réagit à une stimulation visuelle (télévision, personne entrant dans son champ visuel, luminosité...)	1	2	3	4		
3	Réagit à une stimulation olfactive (parfums, odeurs de cuisine...)	1	2	3	4		
4	Réagit à une stimulation gustative (amer, sale, sucré, chaud, froid...)	1	2	3	4		
5	Réagit à une stimulation tactile (tissus, objets, textures des objets...)	1	2	3	4		
6	Réagit aux stimulations corporelles globales (stimulations vibratoires, vestibulaires, balancements...)	1	2	3	4		
Sous-échelle complémentaire							
	Présente une sensibilité spécifique aux contacts avec les zones érogènes (zone sexuelle, par exemple)	1	2	3	4		

COMPORTEMENT :				
NSPP	Jamais observé	Rarement observé	Souvent observé	Systématiquement observé
	1	2	3	4

SCALE 3 - COMPLEMENTARY SCALE TO EVALUATE THE AFFECTIVE AND EMOTIONAL CONDITION.

This scale takes back the items of the scale 1 to highlight the possible difference with the usual state.

- This scale can be used:
- In a psychological assessment
- In an independent way in case of hypothesis that there is a psychic suffering.... It is then a help to seize better the sense of the psychic suffering expressed for a subject

	Imp.	NSP	Lam/NA	Pare/EA	Souvr/EA	4. 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.		1	2	3	4	
2	a plutôt été serein(e)tranquille/paisible		1	2	3	4	
3	s'est montrée plutôt sociable		1	2	3	4	
4	s'est montrée plutôt solitaire		1	2	3	4	
5	s'est montrée anxieuse / stressée (s'est montrée facilement anxieuse)		1	2	3	4	
6	s'est montrée très fatigable		1	2	3	4	
7	s'est montrée essentiellement triste		1	2	3	4	
8	s'est montrée peureuse / craintive (facilement effrayée)		1	2	3	4	
9	s'est mise facilement en colère		1	2	3	4	

During the last two months has the person lived one of the following situations

Durant ces 2 derniers mois, la personne a-t-elle vécu l'une des situations suivantes :

•Oui

•Non

•NSPP : l'observateur ne peut pas se prononcer.

	oui	Non	NSP	commentaires
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 :				

ORGANISATION OF RESEARCH 2014-2017

- 2 post-doctorands recruited
- A group of 77 psychologists and institutions mobilised, working in a variety of institutions in France .
- 2 partner parents and professionals associations.

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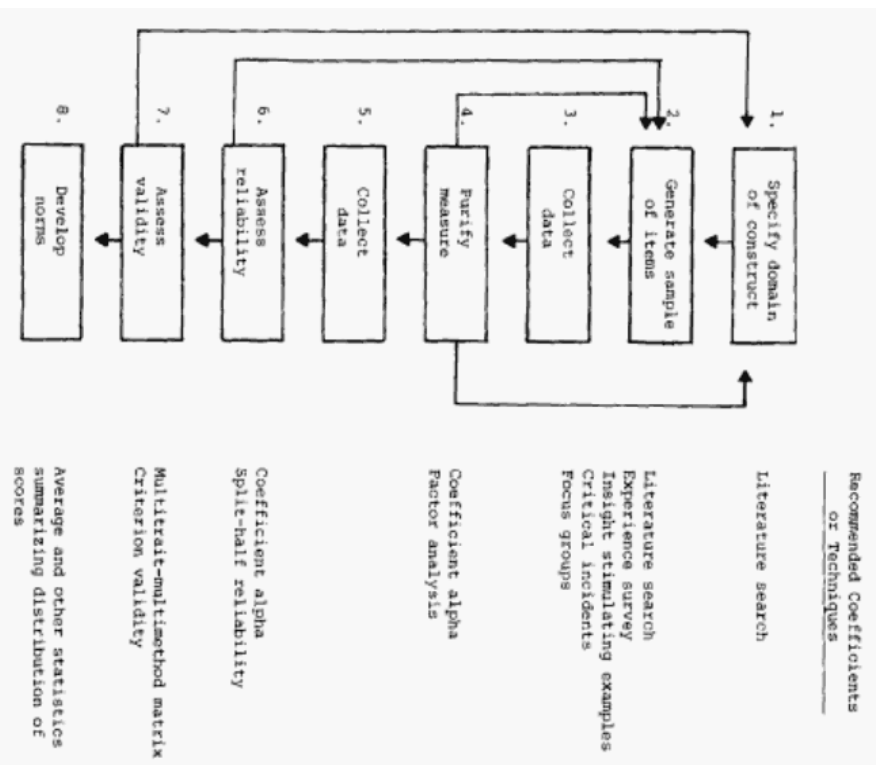


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METHOD

Churchill paradigm (1979)



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VALIDATION PROCESS (METTRE UN CAS AVEC LES SOMMES)

	V1	V2	V3
Dates for assessment	March to June 2015	October to December 2015	December to April 2017
Psychologists accepting the research (160)	23	63	74
Psychologists Involved (103)	18	36	49
Number of cases (3 scales filled in per case) (175)	18	71	86
Children (0-13 years) (45)	3	22	22
Adolescents (13 to 18 years) (56)	3	33	20
Adults (+ 18 years) (72)	12	16	44

QUANTITATIVE VALIDATION

Cronbach's alphas satisfactory

Cronbach's alphas for the entire sample (n=86)			
	Psychologists	Professionals	Parents
Sensory capacities	,76	,80	,76
Attentional abilities	,75	,74	,73
Memory	,94	,75	,76
Communication skills	,96	,95	,92
Reasoning	,85	,86	,88
Spatio-temporal skills	,88	,87	,84
Learning abilities	,72	,89	,88
Socio-emotional competences	,92	,90	,89

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QUANTITATIVE VALIDATION

- Statistical validation :
 - Descriptive statistics. (average, standard deviation, asymmetry) which show a normal distribution of the scores obtained
 - Cronbach's alpha: internal consistency of scales
 - Factor analyses: unidimensional nature of scales
 - Verify the unidimensionality of the scales
 - Determine the hierarchy of the items based on its contribution to the measured dimension (which helped us to “choose” the fundamental items.
- Analysis of items: internal consistency tests (correlations)

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WORKING GROUP ASSESSMENT

Objectives: Collaborative work between researchers and professionals

V1: September 2015	V2: March 2016		V3: March 2017	
Paris	Pau	Paris	Pau	Paris
7 psychologists 1 parent 1 professional	6 psychologists	20 psychologists 2 professionals	5 psychologists	36 psychologists

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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.
- 8 semi-directive interviews

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In collaboration with the Practitioners users of P2CJP (feedback) and building on the Churchill paradigm (1979), we have determined the different dimensions to be evaluated.

Consequently, we have modified the items

- **Rewrite several items**
- **eliminate some items considered not informative**
- **Creation of new items “*ex nihilo*”.**

QUALITATIVE FEEDBACK

- **Pleasure thinking things out together: opens up dialogue on cognitive skills and not just the impairment.**
- **Shared observation grid that allows unforeseen aspects to be thought through.**
- **Mediator for the relation.**
- **Difficulties' of psychologists in institutions, with have lack of time, little knowledge of these people.**
- **Focus on diversities in skills but also identification of difficulties.**
- **Evaluation of certain aspects of skills that may be overlooked / not considered without being reminded of through the items on the scale.**

METHODOLOGICAL PERSPECTIVES

Importance and advantage of combining

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

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PERSPECTIVES

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.

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