



Construction of a reference framework of competences for the accompaniment of children with rare disabilities



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Construction of a reference framework of competences for the accompaniment of children with rare disabilities

CL1: Technical and life skills mobilised in the support relationship



Make use of information analysis, creative thinking in order to find solutions to work-related problems, observation of the child in his or her daily life, communication skills, knowledge of the functioning of the child and of language, interdisciplinary work and positive, open and empathetic attitudes.

- Adopting an analytical attitude.
- Analysing how you support the child.
- Analysing the child's skills and difficulties in a group situation or during an independent activity.
- Hypothesising about the causes of a particular behaviour (e.g. "He throws himself on the floor (...) It's always at midday that something goes wrong (...) He can't express himself in any other way than by his agitation. Perhaps he is hungry.").
- Questioning one's professional practice (e.g. "Understand the child's failure as a possible maladjustment of the task requested").
- Observing the child.
- Making observations of the child's experience, attitude and movements in his or her daily life (e.g. in the educational group, at playtime, in the family, etc.).
- Knowing how to communicate with professionals, parents and children.
- Explaining the child's difficulties and skills to parents in a caring and objective way.
- Adapting one's speech to the parents to be reassuring but without deluding them (e.g. "Remind them that the child will follow at his own pace, remind them that in his case, everything the child is experiencing is normal (...) reassure the parents that they are good parents").
- Having some neuropsychological knowledge of the normal and pathological cognitive development of a child.
- Being knowledgeable about the normal psycho-affective development of a child.
- Mastering the technical skills (tools, methods and know-how) of the profession.

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- Being knowledgeable about motor skills.
- Being knowledgeable about the development of language and communication.
- Adapting one's practice to each child.
- Integrating specific expertise of other professions into one's professional practice (e.g. "Communication is not the business of speech and language therapists, learning is not the business of teachers, taking into account motor skills is not the business of psychomotor therapists").
- Inventing new ways of doing things, tools, teaching methods, games and graphic media.
- Being creative in proposing adaptations of and adjustments to known and mastered techniques.
- Being empathetic, putting oneself in the place of the child, parent or colleague.
- Abandonning habitual patterns of thinking and practice to test new practices through trial and error.
- Looking carefully at what characterises each child: their communication, behaviour, neurocognitive functioning and emotional state.
- Adopting a positive attitude towards the child and helping improve the child's situation and experience.
- Creating a dynamic within disparate groups where "no two are the same age and have the same problems".
- Showing intellectual curiosity about disability, understanding children, neuroscience, etc.
- Collaborating in an interdisciplinary manner.
- Sharing knowledge and sharing the materials used.
- Listening to and learning from colleagues.
- Collaborating (family <-> professionals).
- Adopting a professional attitude of humility, knowing that there is always more to learn.

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- Exchanging one's practice with professionals from different establishments (apart from direct colleagues).
- Training parents or professionals (e.g. training in the use of a communication tool, in understanding a vestibular disorder, etc.).
- Training with professionals who work elsewhere and who allow you to take a step back from your practice.
- Training and information to better understand disability.

CL2: Develop the child's language skills



Analyse what is asked of the child, frame the exchange and create or adjust communication tools according to specific situations.

- Identifying in advance the skills mobilised to carry out a task (e.g. taking psychometric tests, educational session, outing, etc.).
- Identifying the strategies used by the child to communicate: What are his or her preferred channels (visual, auditory or kinaesthetic)? What are their needs (what facilitates or hinders communication)?
- Taking into account all feedback from the child (e.g. behavioural, verbal, postural feedback, etc.).
- Encouraging children to give feedback and make choices.
- Explaining to the child what is happening to him/her, listen to his/her anxieties, be positive, etc. in order to reassure the child.
- Taking into account the child's needs, whether they are emotional, relational, understanding, acquisition, etc.
- Allowing the child to learn in peace.
- Establishing a ritualised, sober and tidy space-time framework.
- Observing all the warning signs of a crisis.
- Allowing the child to anticipate future events.

CL3: Personalise the interaction situation with each child



Modulate adaptations to create situations that are favourable to the expression of the child's skills.

- Creating situations in which to test methods and observe the child's behaviour.
- Bypassing difficulties in order to access the child's hidden skills.
- Being fully aware of the motor, intellectual and postural limitations of each child.
- Listening to and receiving favourably the wishes, needs, desires, etc. expressed by the child.
- Creating visually accessible documents, for example by using pictures or drawings.
- Seeking to create an environment that is conducive to the development of the child's skills.
- Being enthusiastic about creating new tools.

CL4: Adopting an ethical relational posture focused on understanding the child



Understand the child: put yourself in the child's place, rely on contextual elements and use gestures and mimics to help others understand.

- Interpreting a behaviour, gesture or look based on the context, i.e. using a mental substitution strategy to translate the child's communicative intention.
- Putting yourself in the child's shoes to understand what he or she understands, why he or she reacts the way he or she does and what elements of the environment are favourable or unfavourable for his or her communication.
- Having an expressive face and using mimogestures.
- Fighting at every stage of the support process to ensure that the child is accepted by those around him or her and by the institutions or services concerned.

CL5: Proposing adapted activities



Set up activities in accordance with the child's needs and skills.

- Paying attention to the sensory pathways used preferentially by the child to acquire knowledge.
- Stopping an activity when you feel that the child is too tired, even if the objective you have set has not been achieved.
- Readjusting the experimental situation to the child's difficulties and skills.
- Guiding and framing all activities (outings, quiet time, etc.) in order to anticipate the constraints for the child, to make communication tools available to him/her and to manage space-time.
- Articulating collective progress (e.g. of the class group) and individual progress (of each child).
- Working in pairs with colleagues from another profession.
- Questioning the institutional and organisational way of doing things.

CL6: Being involved in the child's life and language development project



Knowing the different ways of communicating and adapting them to the child; ensuring the quality of exchanges with the child and encouraging a climate of trust around the child and his/her life project.

- Finding the means of communication that allows the child to develop his or her language skills and innovating if the tools usually proposed are not suitable.
- Knowing (or learning) Sign Language.
- Mastering a multimodality of communication, whether it is Sign Language, Cued Speech or communication tools such as pictograms or situational drawings.
- Being indulgent towards the special needs of the child.

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- Adapting to the disability to improve the child's environment and daily life and wanting to help the child progress.
- Being involved in the child's life project and language project.
- Collaborating with colleagues in order to offer coherent support to the child's family in the construction of their child's life course.
- Not judging colleagues, parents or children on the basis of expected performance or development.
- Trusting one's skills or expertise and feeling legitimate in the support.

CL7: Practicing mediation and proposing remedial measures



Diagnose the child's skills, propose means of remediation, facilitate cooperation and exchanges between the actors involved with the child.

- Evaluating skills through psychometric assessments.
- Explaining to the child his or her difficulties and skills (e.g. "In the case of auditory neuropathy, depending on the day and the environment, children will hear and understand what is said to them or not").
- Enabling the child to take responsibility for some of his or her difficulties, to develop metacognition (e.g. "Child A. chooses not to go to playtime because he feels that he will not control his anger").
- Disseminating and transmitting orally to the multidisciplinary team the information concerning the skills observed in the child.
- Developing a network of professionals to share practice and to have a care team around the child.
- Acting as a relay to preserve the parent-professional-child link and maintaining a relationship of trust.
- Putting parents in touch with each other.
- Practising non-violent communication.

- Listening in a caring, positive and non-judgmental way (e.g. “Listen to the family, to the parents’ or professionals’ complaints, to the child as he/she is”).

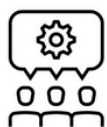
CL8: Designing situations and objectives to serve the child’s well-being



Ensure that the situations experienced by the child are anticipated and constructed in accordance with his/her cognitive, motor and linguistic development and think of the objectives in terms of overall benefit for the child’s well-being.

- Perceiving the overall benefit, i.e. the benefit for the child in his or her daily life, of one or another form of support.
- Enabling the child to express his/her social and communicative skills by creating a relationship of trust.
- Constructing objectives (pedagogical, educational, speech therapy, etc.) in terms of input and respecting the stages of cognitive-motor-linguistic development reached by the child.
- Reflecting on abstract conceptual notions.
- Ensuring an appropriate material environment (e.g. table, chair, light, etc.) in such a way as to allow the child to focus his/her attention (e.g. “For a child who is obsessed with door movements (...) she blocked the door with a door wedge”).

CL9: Practicing interdisciplinarity



Understand and promote a global and integrative vision of disability within a multidisciplinary team in a reflective and collaborative approach.

- Taking into account all psychological approaches and integrating them into one’s practice (e.g. “To have an opening on the cognitive development of the child without losing sight of the psychological aspect”).

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- Being aware of the different profiles of deaf children with vestibular difficulties, with a visual impairment or with various syndromes.
- Understanding that disorders associated with deafness lead to instrumental deficiencies (e.g. memory and motor disorders, neurovisual and vestibular disorders, etc.).
- Summarising a child's follow-up file.
- Supporting interdisciplinary meetings and helping to ensure that people meet in a team and listen to each other.
- Exchanging information between professionals on the skills observed.
- Listening to professionals and parents (e.g. difficulties, opinions, needs).
- Responding to colleagues' requests for advice (e.g. "It's important to eat lunch with my colleague, to be available at break time").
- Explaining to professionals in an objective manner the difficulties and needs of parents.
- Reassuring the team that the rare disability situation has put them at a disadvantage in terms of their skills.
- Helping parents to set an educational framework.
- Learning an augmentative or alternative communication approach.
- Serving as a relay between the superiors and the professionals in the team (e.g. exchanging, requesting information, meeting, etc.).
- Initiating and assisting in the creation of a project, piloting a collective project (other than a child's project; e.g. creation of a specialised class, charter, etc.).

CL10: Questioning the methods of support



Adopt an active questioning attitude before, during and after the moments of exchange with the child. Accept to deviate from the norm in order to be as close as possible to the child's uniqueness and rhythm.

- Knowing the normal development of learning.

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- Being attentive to the child's rhythm (e.g. perceiving signs of fatigue or signs of attention loss).
- Reformulating (orally or in writing) by using different communication tools when the child has not understood.
- Attracting children's attention and motivation by proposing playful activities.
- Offering individual spaces (one adult with one child).
- Adapting pedagogical approaches (e.g. including logicomathematics in mathematics; using communication tools, etc.).
- Adapting one's approach, deviating from the norm, being upstream of "normal" learning, deviating from one's prescriptions to learn in a way that is more adapted to the child's needs (e.g. "Accepting that, because of his or her uniqueness, a child will not fit into the mould of what usually works").
- Calling on the multidisciplinary team in the event of an observation that raises questions or concerns.
- Bringing up the need to adjust the support (e.g. adjustment of individual working time with the child, modification of the individual project, additional resources, etc.).

CL11: Acting quickly and often when uncertain and faced with complex situations



Acting in complex and uncertain action configurations, i.e. being involved in the relationship and being proactive in the face of the child's difficulties.

- Entering into contact with the child easily and quickly: ability to create a link, to attract attention, to reassure, to be positive, to be benevolent and to be respectful.
- Being preventive and alerting quickly enough when you feel that a child is starting to fall a little further behind (out of step with what is expected).
- Inventing a new professional identity.
- Being enthusiastic about working around the child's difficulties to bring out the skills.

- Knowing one's rights and legal recourse in the event of a dispute.
- Taking important decisions as a team for follow-up and care and for parents to take fundamental decisions for the orientation of their child.

CL12: Setting a framework, being a referent in the relationship with the child



“To set a framework” here means “to frame” in the sense of creating a space of freedom in order to respond to the needs of self-determination of children with a rare handicap.

- Being fair and not overprotective.
- Taking the time to explain to the child what is happening (e.g. why a frame is put up).

CL13: Repeatedly questioning one's emotional involvement



Regulate and adjust your emotional involvement in the relationship with the child and always remain focused on the development of the child's skills. This regulation can be based on several strategies such as self-management or the use of supports.

- Being in relationship with the child, being present in the relationship to accompany the child, sharing and living in the moment with the child.
- Focusing on the development of the child's skills.
- Projecting and thinking about the child's future as an autonomous person (life project, job, social life, etc.).
- Asking for advice and soliciting professionals of different specialities to adapt one's activities (e.g. ask the occupational therapist for advice on the child's physical installation or ask the speech therapist for the tools and communication codes adapted to the child) or talking about something that is not going well in everyday life.

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- Delegating and handing over when you feel that you have reached the limits of your skills or abilities (e.g. parents taking time off or professionals abandoning their role as referents).
- Managing one's emotions (e.g. not reacting to aggressiveness with aggressiveness; managing frustration in relation to timeframes that one considers too slow (one's own, that of the parents or within the team), accepting what cannot be changed.
- Showing leadership and assuming one's position.
- Expressing disagreement and daring to tell professionals or the family that they do not have an accurate view of the child.
- Accepting the gaze of others (e.g. for a professional who goes beyond ordinary practice, it is to accept the gaze of colleagues and for a parent it is to accept the gaze of people or family members).

CL14: Managing the child's challenging behaviours



Be patient and facilitative in managing children's non-verbal expressions and behavioural difficulties caused by the rare disability.

- Managing behavioural difficulties (e.g. "Some children turn the desk over", "It's very physical").
- Ensuring that interactions between students are positive (group facilitation).
- Using every conceivable medium.
- Being patient with the child's slow progress (e.g. "(...) because it's tiring in the long run"; "It still takes a lot of energy and time").

CL15: Adjusting practice to the target audience



Demonstrate skill and adaptation in practice, problem-solving and decision-making in relation to the child's disability.

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- Understanding what disability means.
- Taking more time than usual to make preparations.
- Being able to detach oneself from one's universal tools, initial generalist learning, technicality, pedagogy and acquired practices when they are not adapted to the situation.
- Disseminating and transmitting a written report (whatever the level of language) to the multidisciplinary team concerning the skills observed in the child.
- Making preparations with colleagues from another speciality (e.g. "Sit down with the pedagogue colleague or with the speech therapist colleague to make her preparation").
- Being accepted in the parents' home.
- Being curious.
- Having manual skills (e.g. knowing how to use a laminator, glue, to cut out, make sign boards, scratch, etc.).
- Enjoying work with children with very serious communication difficulties.
- Taking an immediate and intuitive decision in the face of a perceived problem or identified situation (e.g. "I'll take it on the fly and act").

CL16: Relying on the child's skills to enable learning



Tendency of the adult to use the child's resources as a support for his/her development.

- Relying on the child's skills to help him/her acquire learning strategies.

CL17: Coordinating overall support



To appropriate the specific language of each partner to facilitate coordination and the development of concerted and coherent responses in supporting the child.

- Coordinating the various forms of care.
- Acquiring medical and paramedical skills (e.g. “Be able to speak to doctors in their jargon (...), be able to understand the speech therapy report or the orthoptic report”).