

**QUICK REFERENCE GUIDE**

# Autism and other PDDs<sup>1</sup>

## Coordinated education and treatment interventions in children and adolescents March 2012

### INVOLVE THE CHILD OR ADOLESCENT AND PARENTS – PAY ATTENTION TO SIBLINGS

Children and adolescents have rights. They should be treated with dignity and their history, personality, routines, own wishes and tastes, abilities and limitations should be recognised. The aim of education and care is to promote their personal development, participation in social life, independence and quality of life.

<b>EC</b>	<ul style="list-style-type: none"> <li>• The uniqueness of the child or adolescent and his or her family should be respected.</li> <li>• The child or adolescent should be informed, involved and encouraged to participate in decisions that affect him or her, taking into account his or her level of maturity and understanding.</li> <li>• The child or adolescent's tastes and interests should be taken into account.</li> <li>• Appropriate means of information and communication aids should be used; in particular, the child or adolescent's usual means of communication should be available to them.</li> <li>• The care plan should be developed together with the parents.</li> <li>• There should be in-depth reflection on welcoming the parents and their child.</li> <li>• Parents should be kept informed and the team should make sure they understand the indications for, objectives of and methods implemented in evaluations and interventions.</li> <li>• Listening to the child or adolescent, parents and siblings, taking their feedback into account and supporting them should be facilitated; different types of support should be offered.</li> </ul>
<b>C</b>	<ul style="list-style-type: none"> <li>• For children or adolescents who rarely communicate orally, alternative or augmentative communication tools should be used as soon as possible and consistently across different environments.</li> </ul>

### EVALUATE THE CHILD OR ADOLESCENT'S DEVELOPMENT REGULARLY

The purpose of evaluating the child or adolescent's development and health is to define and adjust the interventions offered to him or her within the context of a personalised care plan and to ensure that this plan is consistent with up-to-date diagnosis and knowledge. These evaluations should not be limited to giving the child or adolescent a diagnostic label or score, but should aim to highlight his or her resources, potential and adaptive abilities and to determine his or her needs.

#### Initial evaluation performed in the diagnostic phase

<b>EC</b>	<ul style="list-style-type: none"> <li>• With parents' consent, an initial evaluation of the child's functioning should be performed within at least 3 months of the first consultation suggesting a developmental disorder.</li> </ul>
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#### Follow-up evaluation of the child or adolescent

The clinical profiles and development of children and adolescents with PDD differ widely, meaning that regular, multidimensional and multidisciplinary evaluation is required, carried out by professionals who are experienced and trained in examining the different areas listed in Table 1.

<sup>1</sup> PDD: pervasive developmental disorder

EC

- The care team should carry out an evaluation of all the areas listed in Table 1 at least once a year, in order to monitor the child or adolescent's development (functioning and participation) and health.
- A physical examination and annual structured clinical observations should be supplemented by continuous informal observations of the child or adolescent's functioning and participation, carried out across different environments by parents and by professionals during the interventions offered.
- A review giving an overall picture of the child or adolescent's development should be conducted at a meeting, taking into account the unique characteristics of the child or adolescent and of his or her family.
- Evaluation should draw upon the up-to-date expertise of medical doctors, psychologists, allied health professionals and education professionals. Expertise is needed on the development and neuropsychological functioning of children and adolescents with PDD. Evaluations performed by teaching staff in the context of school learning should be taken into account.
- Further evaluations should be carried out every 2 years between the age of 2 and 6 years, and then at transitional ages or during transition periods, to ensure that the care plan is consistent with up-to-date diagnosis and knowledge.
- All care teams should be trained in and have access to the following tools: Childhood Autism Rating Scale (CARS), Vineland Adaptive Behaviour Scale (VABS), Échelle des comportements autistiques [Autistic Behaviour Scale] (ECA), Échelle de communication sociale précoce [Early Social Communication Scale] (ESCS), Psychoeducational Profiles (PEP-3 and AAPEP), and standardised tools for language and sensory-motor development not specific to PDD.

## DEVELOP THE PERSONALISED CARE PLAN IN CONNECTION WITH EVALUATIONS

The purpose of evaluating the child or adolescent's development and health is to define and adjust the interventions offered to him or her within the context of a personalised care plan.

Whatever the child's or adolescent's age, the intensity and content of interventions should be determined taking into account ethical considerations that aim to limit the risks of under-stimulation or over-stimulation.

Parents should receive good quality information as to the expected benefits and possible risks of different investigations, treatments and preventive measures. They have the right to oppose these interventions, as long as their refusal does not risk severe consequences for the child's health (e.g. life-threatening events or severe sequelae) ([articles L.1111-2 and 1111-4 of the French Code of Public Health](#)).

EC

- The results of evaluations should be discussed with the child or adolescent and his or her parents, during the review meeting or afterwards, with the aim of developing or updating the personalised care plan together; a written summary of this should be given to them and sent to the general practitioner with the parents' consent.
- The personalised care plan should include functional goals to be achieved in each of the areas targeted by the evaluation, how these are to be achieved (types of activity, techniques, etc.), the professionals who will implement them (educational, teaching and therapeutic staff) and the deadlines for reevaluating these goals.
- Details of continuous informal observations of the child or adolescent's functioning and participation, carried out across different environments and during interventions, should be exchanged regularly with the child or adolescent and his or her family and, with the parents' consent, between professionals, in order to adjust the functional goals of interventions, to monitor their effectiveness for this particular child or adolescent and to ensure that new skills are generalized.
- If there has been no clear progress after several months, the methods chosen and ways in which they are applied should be discussed and adapted.

Table 1. Areas in which regular evaluation is necessary		
ICF*	Area	Annual or more frequent monitoring of development (EC)
Functioning	Communication and language	<ul style="list-style-type: none"> <li>Joint attention, imitation, initiating communication and respecting one's turn.</li> <li>Receptive and expressive language (spoken and written) and phonological, lexical, semantic, syntactic and pragmatic aspects.</li> </ul>
	Social interactions or socialisation	<ul style="list-style-type: none"> <li>Initiating, maintaining and ending interactions in different situations and different places (play, interactions with family, peers, professionals, strangers, at home, nursery, school, etc.).</li> </ul>
	Cognitive	<ul style="list-style-type: none"> <li>Attention, memory, time perception and spatial perception, anticipation and planning of actions, thought and language processes; particular aspects of functioning.</li> </ul>
	Sensory and motor-	<ul style="list-style-type: none"> <li>Screening for hearing disorders or visual impairment, preferred sensory channels and unusual reactions to some tactile, proprioceptive, auditory, visual, taste or olfactory sensory experiences.</li> <li>Monitoring of development of gross and fine motor skills, control of muscle tone, body image, praxia and gnosia.</li> </ul>
	Emotions and behaviour	<ul style="list-style-type: none"> <li>Psychological and emotional development, recognition and expression of emotions, specific interests.</li> <li>Identification of specific eating behaviours, problem behaviours and conditions under which they occur.</li> <li>Impact of puberty on behaviour (affective and sexual aspects).</li> <li>Screening for anxiety, depression and/or attention deficit hyperactivity disorder.</li> </ul>
	Physical status	<ul style="list-style-type: none"> <li>Medical monitoring, preventive measures and health promotion as for any child (vaccinations, screening for risk of tooth decay, hearing disorders or visual impairment, sleep, diet, cleanliness, etc.).</li> <li>Screening for the following disorders: epilepsy, scoliosis if Rett syndrome.</li> </ul>
Activities and participation	Independence in daily living	<ul style="list-style-type: none"> <li>Independence in personal care (e.g.: washing, going to the toilet, dressing, eating, drinking, taking care of own health, ensuring own safety) and domestic activities (e.g. shopping, etc.).</li> <li>Participation in community, social and civic life (e.g. participating in leisure activities, social life, etc.).</li> </ul>
	Learning, especially school and vocational	<ul style="list-style-type: none"> <li>Monitoring of schooling or professional training (access, maintenance and progress within the curriculum), number of hours of actual education per week, per type of establishment and class (normal or special needs environment) and consistency with personalised schooling plan.</li> <li>Evaluation of school or vocational learning performed by teachers, or tutors in professional training.</li> </ul>
Environmental factors	Family environment	<ul style="list-style-type: none"> <li>Makeup of the family, organisation and relationships within the family; social support available to the family; preservation of the family's stability and quality of life; resources for coping.</li> <li>Family understanding of the diagnosis and their child's development, parents' knowledge and skills regarding PDD.</li> <li>Financial situation and welfare services accessed.</li> <li>Satisfaction regarding current or intended care plan; needs and resources of all members of the family.</li> </ul>
	Physical environment	<ul style="list-style-type: none"> <li>Availability and appropriateness of communication tools and spatial, temporal and sensory cues needed by the child or adolescent in each environment.</li> </ul>

\* ICF: International Classification of Functioning, Disability and Health

## PROVIDE EARLY, COORDINATED AND COMPREHENSIVE INTERVENTIONS

The interventions evaluated demonstrate an improvement in IQ, communication skills, language and adaptive behaviour or a reduction in challenging behaviour in around 50% of children with PDD, with or without mental retardation.

No educational or treatment approach can claim to restore normal functioning or improve the functioning and participation of all children and adolescents with PDD.

Parents should be particularly wary of interventions that claim to completely eliminate all signs of PDD, or to cure their child.

### Provide interventions within 3 months of diagnosis

<b>B</b>	<ul style="list-style-type: none"><li>• A personalised care plan consisting of coordinated and comprehensive early interventions should be implemented within 3 months of diagnosis for all children with PDD, whether there is associated mental retardation or not.</li></ul>
<b>C</b>	<ul style="list-style-type: none"><li>• As soon as a developmental disorder is noted, if comprehensive interventions are not available within 3 months of diagnosis, the parents and their child should initially be offered targeted interventions focusing on the development of communication and language, in order to improve social interaction between the child or adolescent and his or her environment. Comprehensive interventions should then be implemented as soon as possible.</li></ul>

### Provide coordinated and comprehensive interventions

<b>B</b>	<ul style="list-style-type: none"><li>• Personalised, coordinated and comprehensive interventions should be started before the age of 4 years, based on an educational, behavioural and developmental approach.</li><li>• A comprehensive approach should not involve the juxtaposition of educational, teaching, rehabilitation or psychological practices with very heterogeneous or eclectic techniques.</li><li>• A common means of communication and interaction should be used with the child.</li><li>• Interventions should be personalised and prioritised according to the initial evaluation and ongoing development of the child with PDD, and should take typical stages of development in the different areas into account.</li><li>• Interventions should aim to improve the child's development in several areas (the comprehensive approach): imitation, language, communication, play, social interactions, motor organisation and planning of actions, adaptiveness of behaviour in everyday life; emotional and sensory areas should also be taken into account (expert consensus).</li><li>• The parents should be involved to make sure that means of interaction with the child are consistent and new skills are generalised: the option to take part in educational and treatment sessions, support, training or patient education programmes should be offered, but this should not be compulsory.</li><li>• Interventions should be organised in ways that have been proven to be effective: trained and supervised teams, a ratio of one adult to one child, a weekly schedule with at least 20-25 hours per week. These minimum time limits, which should respect circadian sleep rhythms depending on the child's age, include periods of schooling with appropriate individual support.</li></ul>
<b>C</b>	<ul style="list-style-type: none"><li>• The child's physical environment should be adapted and structured according to his or her particular needs (space, time, sound, etc.).</li><li>• Strategies for preventing or reducing the consequences or frequency of challenging behaviours should be integrated.</li><li>• From the age of 4 years, specific interventions should be offered that target one or two particular areas, either alone if the child or adolescent has no associated mental retardation, or in addition to the comprehensive interventions offered if the child or adolescent has a poor level of development of communication, social interaction and cognitive functioning or if his or her skill levels vary widely across different fields.</li></ul>
<b>EC</b>	<ul style="list-style-type: none"><li>• From the age of 4 years, decisions to implement or continue interventions should be adapted using different systems in accordance with results obtained from evaluating the child or adolescent's development and the severity of symptoms.</li></ul>

## CONTROL DRUG PRESCRIPTIONS

No drug treatment cures autism or PDD; however, some medications are necessary in the treatment of disorders frequently associated with PDD (e.g. epilepsy) and others may have a non-systematic and temporary place in the implementation of educational and therapeutic intervention strategies in children or adolescents with PDD.

After examination of published data, there is no consensus as to the most appropriate drug strategy for behavioural disorders (few randomised controlled trials, limited numbers of patients, frequent adverse events, mostly drugs without marketing authorisation in France).

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- Medical opinion should be sought to screen for a physical cause if there is a sudden or unexplained change in behaviour, as this change may be a sign of underlying pain. Drug treatment or an intervention aimed at reducing behavioural disorders may be started in parallel with medical investigations, but should not be used as a substitute for these.
- The recommended drug treatments should be prescribed in cases of pain, epilepsy or physical comorbidities, which are currently under-diagnosed.
- Any drug prescription for a psychiatric disorder associated with PDD (depression, anxiety), sleep disorder or behavioural disorder should be recorded in a personalised care plan, which should include parallel investigations for factors contributing to the disorder's onset or maintenance (including environmental factors) and non-drug educational or therapeutic interventions.
- Parents should be given clear information about the indication for, adverse effects of and potential risks of treatment; other drug treatments used should be identified with them, including self-medication; their consent to the treatment should be obtained.
- Initial prescriptions for psychotropic drugs should only be given very rarely, by specialists in child neurology or child and adolescent psychiatry, or by a doctor very familiar with the treatment of behavioural disorders in children and adolescents with PDD. Treatment should be temporary and the means of renewing prescriptions and monitoring treatment, especially safety, should be communicated to the general practitioner.
- The drug should be changed if treatment is ineffective: there are no arguments in favour of combining psychotropic drugs.
- A standardised treatment monitoring form should be made available to the prescriber, including details of the drug prescribed (start and end dates of prescription, efficacy, adverse effects, doses, compliance), clinical data from evaluation scales (e.g. Aberrant Behavior Checklist [ABC], Childhood Autism Rating Scale [CARS], Vineland scale [VABS]) and the results of further evaluation.

## ENSURE THAT INTERVENTIONS ARE CONSISTENT AND COMPLEMENTARY WITH CONTINUITY THROUGHOUT THE CHILD OR ADOLESCENT'S LIFESPAN

EC

- The care team should produce a written personalised care plan that is consistent with and complements the child or adolescent's and their parents' life plans and, if the child or adolescent is recognised as disabled by the Regional Home for the Disabled (MDPH), their personalised compensation plan (PPC) and personalised schooling plan (PPS).
- Within the care team, one professional or partner should be designated responsible for ensuring that interventions are coordinated so as to implement the child or adolescent's care plan; tasks and means of designating these should be defined in the institution's or service's contract.
- Professionals should be vigilant and prepare for transition periods and situations.
- A common or consultable file should be used that respects the codes of practice for each profession, updated once a month.
- With parents' consent, information essential to understanding the child or adolescent's functioning and development should be passed on whenever the organisation or team is changed.
- Communication between professionals should be supervised at least once every three months by an experienced professional, psychiatrist or psychologist, and recorded in writing.
- Regular training should be provided every 2 or 3 years to update professionals' knowledge of autism and PDD and the interventions recommended.
- Informative and awareness-raising meetings should be arranged for school staff, and in particular teachers, covering the characteristics of children and adolescents with PDD and adjustments that can be made to facilitate their learning (structuring space and time, adapting information with visual aids, breaking down learning stages, etc.).

### Grades of recommendation

<b>A</b>	Established scientific evidence	<b>C</b>	Low level of evidence
<b>B</b>	Scientific presumption	<b>EC</b>	Expert consensus