

ASSESSMENT WITHIN THE CONTEXT OF EARLY INTERVENTION TO CHILDREN AT RISK AND WITH DISORDERS AND TO THEIR FAMILIES

Manifesto of the Eurlyaid working party



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1. Introduction

EURLYAID is a working group of academics, service providers and representatives of parent associations concerned about early intervention from different European Community (EC) countries. EURLYAID is part of the non-governmental organization ALEFPA-Europe and its work is supported by an EC grant in the framework of HELIOS-II-Programme.

This manifesto on assessment follows the first manifesto (Elsenborn, Belgium 1991), in which the group defined its general early intervention framework. The assessment manifesto is based on group meetings held in Barcelona, Spain (October 6-8, 1994) and in Deinze, Belgium (October 12-15, 1995). The manifesto provides definitions and suggestions regarding early aid to small children at risk and with disabilities and their families.

2. Purpose of assessment

The purpose of assessment is to obtain information needed to promote the quality of life and the development of children at risk and with disabilities. The EURLYAID group defines child development as a transactional process in which developmental outcome depends on continuous dynamic interactions of the child and the experience provided by his/her family and social context (e.g. Sameroff & Fiese, 1990). Based on this stance, the object of assessment may be a child, a family, a social context or interaction patterns between actors.

Child development promotion activities can be aimed at primary, secondary, or tertiary prevention of early childhood injuries or disabilities due to inadequate environmental conditions. The purpose of primary prevention is to reduce new cases (incidence); secondary prevention reduces existing cases (prevalence); and tertiary prevention reduces reoccurrence or complications of condition.

The assessment questions associated with prevention efforts take into consideration the following objectives : (1) the identification of agents at risk in circumstances known to be causally associated with injuries (primary prevention : e.g. identification of and intervention for mothers suffering from AIDS, alcoholism, or drug abuse); (2) disabling consequences (secondary prevention : identification of and intervention for children at risk of developmental disabilities); (3) handicapping conditions (tertiary prevention : prevention of secondary conditions associated with disability).

Assessment instruments should be selected in accordance with the focus of assessment questions. The scope of questions can vary from specific to comprehensive depending on the purpose.

In sum, the purpose of assessment is related to the following information needs :

1. to identify children at risk;
2. to define and document such a child's health, functional, psychological, and/or

- social condition; 3. to define and document parents' and family's expectations, needs, concerns, and/or competencies;
4. to define and document outcomes of intervention.

The EURLYAID group proposes that a comprehensive child assessment should include profiles of a child's functional abilities (e.g. International Classification of Impairments, Disabilities, and Handicaps (WHO, 1980); ABILITIES index (Simeonsson & Bailey, 1991) as well as diagnosis of developmental status and intervention needs.

Determination of eligibility criteria for services should be based not only on diagnostic categories, but also risk factors for children without significant delays.

Assessment data should provide useful information for the development of Individualized Service Plans. In other words, all assessment should be targeted according to the goals of intervention.

It is recommended that assessments are as unobtrusive as possible for the child and the family.

A primary focus of assessment should be the child's and family's individual strengths. The parents should have a central role in determining the nature and extent of assessment of their individual or family characteristics.

3. Assessment characteristics

3.1. Assessment approach

Three approaches can be distinguished :

- The qualitative development approach which defines the child's level of function, regardless of age, and the functional strategies which s/he uses to execute a given task.
- The psychometric approach compares the child's performance in a standardized situation with that achieved by the same age children in the same situation. This enables one to situate the individual vis-à-vis the general population which shares the same characteristics. It concerns various aspects linked to the way in which the child's personality operates (intellectual, psycho-emotional, etc.)

The psychometric test is only of value when the results from the tests are analysed in a detailed manner. A numerical report is thus always insufficient.

- The eco-cultural approach observes the child's behaviour and interaction in various ordinary situations encountered in daily life. The child family interaction is to be given special attention.

The choice of an evaluation approach must be based on objectives defined beforehand. No approach can a priori be eliminated. A combination of different approaches is necessary to contribute to our knowledge of the child, to enable maximum individualization of the intervention programmes and to guarantee a maximum degree of coherence between them. The link between the aims of the intervention and the means should be clearly defined.

Analysis of the child's functional abilities can often be taken as a starting point for the assessment.

In an appropriate assessment, quantitative and qualitative data are combined in order to gain a comprehensive view of the child's needs and strengths.

Finally, the parents must be closely involved - in a real partnership - in each phase of the assessment. They should be correctly and clearly informed about the reasons behind assessments.

3.2. Assessment over time

One can separate initial and continuous assessment :

- Initial assessment has four stages : diagnosis; the choice of intervention; orientation criteria towards an intervention centre; a plan of the individualized service.
- Continuous assessment can be done day after day and covers follow-ups, short-, medium- and long-term assessments, and specific assessment required at a given moment. Continuous assessment is carried out until the objective is reached or it is no longer deemed appropriate.

It is important to pay attention to the coherence of the assessment at a given moment, but the value of a longitudinal perspective should not be overlooked.

3.3. Assessment phases

Assessment includes at least five phases :

- 1) planning (why, who, how, with what, preparation of the material);
- 2) test performance;
- 3) interpretation, to include the written report and the preparation concerning the avenues to be explored;
- 4) sharing the collected information with the parents and discussion with them of the possible avenues;
- 5) follow-up which enables one to monitor whether the results of the intervention satisfy the parents and the team and whether it needs adjusting.

The parents have a role to play in all stages of the process. They must be involved right from the moment the objectives and the assessment strategies are chosen. Their observations play a role in the performance of tests and above all in the interpretation of the data and the choice of the various avenues which can be explored. Time must, therefore, be

devoted to informing and involving the parents in each of the phases. A co-operation between parents and professionals in a real partnership has to be aimed at (Bouchard & al., 1994).

In the planning phase, the entire team, not an isolated professional, decides on the appropriateness of assessment in collaboration with the parents. It is the professional who implements it in the interest of the child and the parents.

In the test phase, the parents, the examiner, and the child should get to know each other before embarking on assessment in order to enable the child to be in the very best condition to demonstrate his/her skills. The duration of the test phase should be adjusted to the needs of each child. Time is an essential factor; trying to save time may jeopardize the child's ability to fully express him-/herself. Accordingly, the parents may need extra time to express their expectations and needs.

3.4. *Sharing the assessment data*

The information collected by the various observations of the child should be shared with the parents and those involved in working with the child. This task is important because it facilitates the child's start in an intervention programme and helps the team to accommodate to the child. When due care is not taken, the results can lead to a negative impression of the child which arrests all prospects for his/her development. On the other hand, non-expression of the results may lead to suspicion and to demotivation.

A specific period of time for exchanges concerning the assessment data would appear necessary for all persons involved. A written presentation accompanying this process may help other indicators to be visualized and to provide answers to questions which may arise at a later stage. This approach is demanding because it leaves physical traces and its impact is far greater.

The terms used must be positive without blurring the limitations : it is important to be as understanding as possible and not to inhibit and limit.

4. Assessment and intervention

Assessment within the context of early aid reveals its true significance when it is at the service of "intervention" on behalf of the child and its family.

All data collected during assessment should enable the team to meet the child's needs, and also to help him/her "to do", "to go", "to be", "to be with", "to be physically well", "to have". The difficulty resides in choosing the most suitable situations, the most beneficial situations for his/her development and self-fulfilment by listening to the child's wishes and not only the adults' (examiner, parents, those working with the child, ...) wishes and aspirations. What is suggested to the child should depend not only on assessment but also on a vast number of characteristics (stress, resources, needs) present the child's entourage, who, like the child, are concerned with early aid. Intervention involving one person obviously impacts on others. Child assessment does not, therefore, enable all the priorities for early intervention to be established since other agents are involved in early aid, including

especially the parents. With reference to the sharing of the information mentioned above, what is called for is an open discussion of the results and a joint decision on what will be done on a daily basis.

Note : all the various assessments together will never enable the child to be understood fully. In an attempt to get closer to his/her complexity, a variety of means should be used. They should be adapted to be defined objectives, circumstances and the child's living context, to the preferences of other people present in the child's life, and the specificities of the child's disability. Methods are not only "measuring" tools but also involve observation strategies, strategies to collect information which are chosen from among the following : observation of the child in standard situations, in free situations, in interactions with his/her peer group or adults, in new or familiar situations. The information collected from the child's entourage also provides a series of data. It is the complementary observation by professionals and parents which offers the best understanding of situations.

The participation by and involvement of professionals with different specialities and disciplines enriches the field of investigation. However, the expectations and needs of families show that this is not always desirable when one wishes to avoid overloading the child and intrusive action. Transdisciplinarity should be preferred when possible. This means that one person should take the role of co-ordinator to ensure that the assessment remains consistent over time, while at the same time guaranteeing a co-ordinated approach.

5. Ethical aspects of assessment

Assessment requires ethical discussions because it concerns people and may have significant consequences for their lives.

In the appendix, we list a few ethical points which we consider important to discuss within the team. However, the list is not exhaustive.

6. The challenges involved in assessment

Assessment of a child with disabilities poses a series of specific problems which should be considered in order to give a meaning to the assessment and to avoid side-stepping the issues. The problems may concern those who are involved (the child, the examiner, ...) in the assessment, the instruments used, and the situation being investigated. They all have an impact linked to results.

Recommendations to limit the problems relating to the child's individual characteristics

- Do not see the child only in light of its disability because it may hide abilities in other areas of development.
- Do not lose sight of the fact that medication and the child's state of wakefulness may affect performance levels and the strategies used by the child.

- Do not endeavour to explain repetitive, stereotypical behaviour on the basis of a single unidimensional model : the meaning of this type of behaviour may vary considerably from one child to another and from one situation to another; stereotypical behaviour can hide abilities in other fields.
- Do not define a general level of development on the basis of assessment in a single area because most young children have uneven levels of development.
- Compare observations which precede and follow the test with the assessment results. Similarly, carry out a comparative analysis of the results achieved against those collected at the time of previous assessments.

Recommendations to limit the problems relating to the examiner

- The examiner must be experienced in testing procedures and have empathetic understanding of disabled children. A lack of such expertise may result in the choice of inappropriate areas for assessment and the selection of inadequate test methods, which would lead to the wrong conclusions.
- The children have a right to be examined by a qualified professional who does not hold preconceived and/or erroneous ideas concerning the effects of a disability. The examiner should thus avoid prejudiced interpretation of the assessment results.
- Assessments must be carried out in the presence of a person the child trusts and with whom the child can best communicate. In this way, the difficulties encountered in interpreting the child's answers are reduced. If necessary, one may also use alternative and specific communication methods (e.g. Bliss, sign language, ...).

Recommendations to limit the problems relating to the instruments

- Bear in mind that most tests are - from the methodological point of view - not suitable to measure the aptitudes of a child with severe or specific deficiencies. Thus, for instance :
 - the data collection method may impose restrictions, in that the results from the tests, observations and parent interviews may be fairly divergent;
 - the material and objects used in some tests are old-fashioned or inappropriate;
 - the duration time of the test may prevent its use;
 - the range of assessment tools is fairly small for pre-school children and those who are unable to communicate orally or have limited functional abilities.
- Bear in mind that most of the tests are not prescriptive and cannot provide an indicator for the orientation of learning or teaching programmes.
- Also bear in mind that :
 - standardization of the tests is based on populations which do not include disabled children;
 - it may be difficult to compare the results from the various tests because of the different scoring procedures and of variations in test situations;
 - the data base is insufficient to "quantify" the performance of one child compared to another with the same disability.

Recommendations to limit the problems relating to the assessment situation

- Choose bright and well-ventilated sites which are adapted to the child's needs, because the physical surroundings influence a child's performance level.
- Give the child enough time to adapt to the assessment situation which is typically unfamiliar and/or artificial to the child.
- Ensure that the child is in the best possible and the most comfortable position, both physically and psychologically.

General recommendations

- A test cannot be interpreted adequately without reference to the theory on which it is based.
- It is most important to avoid any confusion between the nosographic terms used (e.g. minor mental deficiency, cerebral motor disability) and the child. Indeed, too often the "label" given to a child assimilates him/her to a category of people mistakenly considered as uniform.
- In addition to quantitative results, we recommend that assessors report what the child is able to do in developmental terms, from the least to the most, from the general to the more specific, from the easy to the more complex and to make a detailed analysis of his or her functional skills.

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Appendix : Ethics : some points to be discussed

1. The appropriateness of assessment, its justification, the means to be used and the best moment in which to carry it out have to be considered at all times and for each child and family.
2. The assessment must be useful and aim to improve the child's quality of life. It can be justified only in relation to the child's interests and to those accompanying him/her. In an educational context, this excludes any assessment for any other reasons (research, diagnosis, functioning rites) except if the parents have been informed and have explicitly and freely consented to this.
3. Parents must have the right to receive all information on evaluation without any exception, and this in a language that is comprehensible to them.
4. Respect must be shown to all parents if they have difficulties in coping with the assessment and in sharing the results. The professionals must establish - for each parent - the best conditions in which the evaluation is carried out and the results are shared.
5. Parents must at all times retain the right of choosing to participate or not in one or other phase of the assessment.
6. The conclusions from any assessment must not jeopardize the child's rights and social image.
7. Legislation in EU Member States ought to be brought in line with the basic principles mentioned in this manifesto.

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(10.1999)

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