THE C@ROLIN@ SOFTWARE
A System for Monitoring Skills Development of Children with Down Syndrome

Salvatore Cuomo, Aniello Murano and Francesco Piccialli
Faculty of Science MNF, University of Naples Federico II, Naples, Italy

Keywords: Design and development methodologies for Healthcare IT, Assessment, Databases and datawarehousing, Datamining, Support for clinical decision-making, Numerical Extrapolation.

Abstract: The study of medical protocols for monitoring and analyzing the cognitive development of children with disabilities is a fundamental research area. In this context, a well established curriculum-based assessment is the *Carolina Curriculum for Infants and Toddlers with Special Needs*(CCITSN). This is a suitable curriculum for early intervention programs, where sequenced items data collection and analysis allow for monitoring, incremental program change, and recognition of areas of relative strength and weakness in children with mild, moderate, or severe disabilities.
This paper describes the design and the development of an information system based on a client-server software application, named C@rolin@, which carries out all CCITSN abilities and more, for the monitoring and the analysis of data coming from a medical protocol for children with the Down syndrome. In particular, by means of user-friendly graphic interfaces, the C@rolin@ software helps users to add, modify, recover, and analyze data, to watch singular and aggregate data via customized reports, as well as to interpolate data among children to determine or prevent specific behaviors.

1 INTRODUCTION

The study of medical protocols for monitoring and analyzing the cognitive development of children with disabilities is a very spread out research area (c.f., (R. S. Chapman, 2000)). Many studies in this field are based on *means-end behavior*, which involves a painful execution of a sequence of steps to achieve a goal and occurs in situations where an obstacle preventing achievement of the goal must be initially removed (Piaget, 1953; Woodward, 1971). Means-end is considered a fundamental cognitive milestone due to its strong correlation to the field of verbal and nonverbal *intentional communication* (E. Bates, 1979a; E. Bates, 1979b) and its relationship to understanding the intent of other actions (S. Bruce, 2009). While the majority of means-end research on children without disabilities focuses directly on the developmental sequence and the age at which means-end behaviors are achieved, most of the research on children with severe disabilities emphasizes how the development of means-end is connected to intentional communication and language development. In this contexts, it is well stated the importance of creating accessible opportunities for children with disabilities to observe others solving means-end problems (that is, problems in which one must act on an intermediary to attain a goal object).

Means-end behaviors can be assessed using formal assessment tools, informal commercial tools, or through structured informal assessment. In the case of young children, the assessment is often done in the context of play, but adults can create opportunities for children of any age to display means-end skills as well. In this context, the *Carolina Curriculum for Infants and Toddlers with Special Needs* (CCITSN) (M. Nancy, 2004) is a well established curriculum-based assessment that provides intervention strategies appropriate for young children with disabilities. In particular, it allows for early intervention programs, where sequenced items data collection and analysis allow for monitoring, incremental program change, and recognition of areas of relative strength and weakness in an individual infant or child with mild, moderate, or severe disabilities. The curriculum is based on normal sequences of developments but does not assume even development across domains. The curriculum recognizes the importance of teaching adaptive skills that temporarily or permanently replace normal skills as neces-

Cuomo S., Murano A. and Piccialli F..
THE C@ROLIN@ SOFTWARE - A System for Monitoring Skills Development of Children with Down Syndrome.
DOI: 10.5220/0003135401800185
In *Proceedings of the International Conference on Health Informatics* (HEALTHINF-2011), pages 180-185
ISBN: 978-989-8425-34-8

sary. It provides functional activities, suggestions and suitable adaptations to address sensory/motor issues and stresses the importance of family involvement throughout the assessment-intervention process. Practically, CCITSN allows to collect continuously data on the children's progresses along the curriculum. The quantitative information are also compared with qualitative data collected by interviewing both children and their relatives. The interview analysis is used to explore children's perceptions and experiences through the identification of lexical fields, keywords and phrases. The interviews produce data to gauge the effectiveness of the interventions, programs and transition plans for each of the different settings. All the acquired data will be used to check whether a child develops the right skills in accordance to his age. If this is not the case, the data will then help to determine the right program to follow to recover such skills. Finally, we report that recently in Italy the Carolina Curriculum has been adopted as a basic service within several local Regional Service Systems (ASL).

Although the advantages of the Carolina Curriculum are intrinsically clear and well established (see (E. Del Giudice, 2006) for a useful recent application), its practical application suffers from the huge quantity of information it has to collect and handle, which is done continuously along the specific child program. Indeed, we recall that the curriculum is divided into 24 logical teaching sequences covering five development domains (i.e., *cognition*, *communication*, *social adaptation*, *fine motor*, and *gross motor*). Each curricular item is then divided in six areas (i.e., *title*, *objective*, *materials needed*, *teaching procedures*, r*outine integration strategies*, and *sensorimotor adaptations*). Each of such areas is then divided in several sequences. Totally, the curriculum allows to monitor 531 abilities and the goal here is to ensure that each child acquires all these abilities by the end of the monitoring process. This huge amount of data (and thus of work) makes quite impossible to manage the Caroline Curriculum by hands and general commercial software tools are less appropriate to collect and properly elaborate all these data.

The aim of this work is to design and develop a full web application software system, named *C@rolin@*, based on the Carolina Curriculum framework. This software allows, from one side, to efficiently collect, represent, and evaluate the relative data along the curriculum and, from the other side, to support educators, doctors, parents, volunteers, therapists, and the children themselves in the assessment-intervention process of the children involved, all as required by the Carolina Curriculum. Hence, C@rolin@ fully takes care of all 531 items on which the evaluation table of the Carolina Curriculum is based. Moreover, C@rolin@ allows all people involved in the children development skills process to have a concurrent and real-time access to all data, with respect to their own access privileges, and to add, modify, elaborate, and organize them. Teachers and doctors can check at any time the performance of all children activities and use this information to better plan the future activities. Also, they can make data interpolation among children (also using history data) to better organize the future programs as well as prevent problems/failures, of any sort, in the future. As one may expect, C@rolin@ benefits of all positive aspects of a client-server software. Among the others, we report that it can avoid data duplication, ensures data coherence, allows using a common tool for monitoring results across different development areas, allows to easily extract aggregate data to be used in external systems, etc.

Practically, C@rolin@ is realized by means of the following implemented modules:

- Evaluation Tables;
- Identification of emerging skills, the consolidated ones, and those not yet acquired;
- Data analysis: score, development age, development quotient;
- Overall Program Planning;
- Development Progress Chart (DPC).
- Working Plan: daily, weekly, and monthly tasks description;

2 THE SOFTWARE ARCHITECTURE

The C@rolin@ software has been implemented over a three–tier infrastructure, that is, a client–server architecture in which the *presentation*, the *application processing*, and the *data management* are logically separate processes. We have chosen to use a multi-tier architecture as it allows to develop a flexible and reusable application. Indeed, by breaking up the C@rolin@ software into tiers, future developments of the software may involve only a specific layer, rather than to rewrite the entire application over.

Specifically, the C@rolin@ software has a client tier, an application tier, and a data tier, working as follows:

- **Client Tier.** This is the topmost level of the application. It is composed of the front-end pages of users (doctors, teachers, families, ecc) interfaces and displays information related to these actors. These interfaces are described in more details in the following;

- **Application Tier.** This tier is composed of the PHP (version 5) modules implementing the business logic of the application. Most of these modules are responsible for processing the user input from the upper tier and for loading and storing data in the lower tier. Note that, at this level, it is hidden the way the storage of data is implemented;
- **Data Tier.** This tier consists of a relational database server, deployed by using MySql as a database management system, where all information are stored. In particular, all relationships between the different domains with sequences and items on which the Carolina Curriculum is base have been implemented. This tier keeps data neutral and independent from the other two tiers.

The application is fully accessible with a web browser. The navigation is facilitated across the simple interfaces based on menus and navigation bars. No browser plug-in installations are needed, except for the Java runtime to run applets. It is worth noting that the system has been tested on recent versions of the most common browsers (i.e., Internet Explorer, Mozilla Firefox and Google Chrome).

The database has the aim of recording for each child all the evaluation data, their elaboration, and in particular the data scores. Also, the database offers a useful centralization of data, in such a way that every subject involved in the Carolina Curriculum can easily access to the children information database, according to their access privilege, in order to add, modify or simply watch children data and programs.

In order to get a further logical separation at the presentation level (i.e, at Client Tier level) we also use in C@rolin@ a Model View Control (MVC) architecture. Note that while the three-tier infrastructure is mainly physical, the MVC architecture pattern establishes a division of responsibilities between components at a use case level, without mentioning physical boundaries (in deployment terms).

The overall software architecture allows to access easily to clear tables and charts to fully understand the development level reached by children, as well as the program they have been following since their enrollment under the Carolina Curriculum. The software is built in such a way it can offer data analysis as well as data comparison to determine or prevent future events. Finally, the software is build in order to easily support the export of aggregate data to be used in external systems.

3 DATA ANALYSIS

As it is well known by medical expertises, the appropriate use of the Carolina Currriculum is based on the following main steps: (i) Determine initial children status, (ii) Plan the right program and implement it, (iii) possibily, change the program according to the ongoing collection of data. These steps are implemented by using a simplified Elettoronic Patient Record (ERP), as we have implemented (see Figure 1). The ERP is composed of eight panels, which allows to make, in a sequential way, the following main tasks required by the Carolina Curriculum: *preliminary evaluation*, *data store*, *data analisys*, *program plan*.

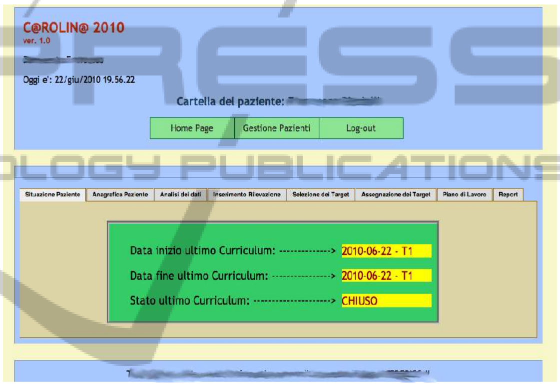

Figure 1: The ERP along with its eight panels.

The user-friendly graphic interface allows the operator to easily open a new curriculum or a child (evaluation table), record his data, as well as calculate and show all relative scores. Then, by using clear data reports built apon this information, the operator is assisted to set up the most appropriate program for the child, as well as to monitor his developments along the time. Also, the reports help the operator to decide wheter it is better to modify the planned program or stay with it (see Figure 3). This guarantees that every child will have his own program, corresponding to his specific needs.

In Figure 3, we show the `Data Report Panel` that reports, by means of tables and development progress charts, the following information: development age, development rate, partial and global performance indexes of the applied program. All these data are calculated (and thus shown) for each domain area and/or sequence. Also, it is possible to show current data variations with previous evaluations. Using these data, the operator has always in real-time the complete and detailed picture of the children skills development.

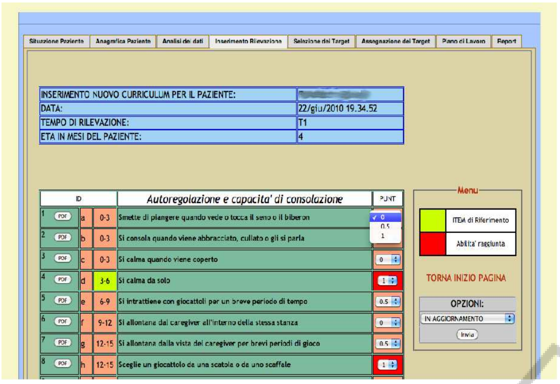

Figure 2: The new child curriculum panel.

It is worth noting that such a panel organization is hard to reproduce by using classical software tools such as spreadsheets, because of the huge amount of data to be handled and the continuous adaptations of the program to the specific needs of the children unrolled under the curriculum.

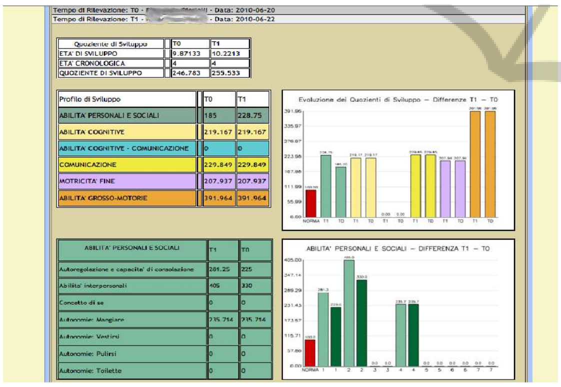

Figure 3: The Data Report Panel.

The modular functionality of the C@rolin@ software (i.e., its break down in the above described panels) reflects the modular architecture of the software. The latter is very useful in the case one has to modify a module and even more in the case a new module for a specific task has to added in the future. In this case, indeed, it is not required to modify the entire software, but only the part under interest.

Observe that also the Carolina Curriculum has been efficiently thought in a modular way. This is just because, as any medical protocol, it is characterized by fast and deep changes along the time. The Carolina Curriculum is now days at its third edition and, thanks to its modularity, every new release has been obtained by simply adding new tasks, without changing the basic structure of the curriculum. In the same way, one can add a new domain area in the C@rolin@ software by simply updating the database. Technically, it is not required to touch the graphic interface as it is a web based application. Indeed, it is automatically generated by means of the structure of the Curriculum stored in the database). So, the new domain area is added to the graphic interface for free.

3.1 A Guided Planning Program

The C@rolin@ software is developed in order to set up a specific program for each patient. This is done by collecting and evaluating data along the time. At each evaluation stage, the software select a list of 31 skills not acquired yet (corresponding to item data scored with 0) and 31 emerging skills (corresponding to item data scored with 0.5). The operator then selects at most six specific skills among them to plan the program. The planning consists of associating the selected items specific daily tasks (made in routine), by means of ad-hoc strategies and specific tools. The main children daily routines are: *Eating*, *Sleeping*, *Dressing*, *Playing with adults*, *Playing alone*, and *Reading*. The program results are stored in the database along with the score achieved and the main difficulties registered. By using overall information stored in the database such as development age, development rate, family conditions, etc. the software suggests the right planning program for improving the children skills.

Suppose that we want to compute some values in the `Data Report Panel`, such as development age, development rate, partial performance index of the applied program, for each domain and sequence. This is performed by applying specific formulas (defined by the Carolina Curriculum), reported in the following, each one developed in a specific module of our software. For the development rate, we first have to calculate the weight (PI) of the Item, as follows

$$PI = \frac{PTA}{NI} \quad (1)$$

where PTA is the typical period of a skill reached and NI is the number of items.

The development age is:

$$ES = PG * PI \quad (2)$$

where PG is the row score.

The development rate is:

$$QS = \frac{ES}{EC} \times 100 \quad (3)$$

where EC is the chronological age.

The partial performance index of the applied program is equal to the performance between two subsequent evaluations. Formally, it is expressed by the following formula

$$IE = \frac{ES(t_n) - ES(t_{n_1})}{T} \quad (4)$$

where T is therapy time.

The overall information obtained by the Carolina Curriculum therapy are elaborated by different software modules and for each patient the results of ad-hoc planning program is reported in a Develop Progress Diagram (DPD) as showed in figure 4.

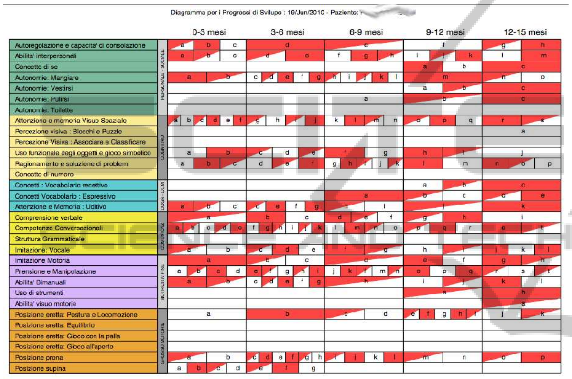

Figure 4: A Develop Progress Diagram (DPD). Blank cells correspond to score 0, red cells correspond to score 1, the remaining ones to score 0.5.

By means of the DPD, the operator at a glance can immediately observe the children skills status.

4 PRACTICAL EXPERIENCES

In this section, we underline few interesting potentialities of the implemented software in the analysis of data. The presence of a central database permits the comparison of acquired skills from different patients and the efficient monitoring of the program on each children. The difference with a classical spreadsheet is also in the possibility to get out information through the opportune queries to the database and to combine information through formulas seen in the previous section.

4.1 Analysis of Development Trajectory

Assume that we want to extract some medical information from a number of patients enrolled under the Carolina Curriculum. This can be done by means of ad-hoc queries, which are performed by an authorized operator. In the following, we report fews examples of such queries and the consequent analysis on real data.

```
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 10 AND T_RILEV = 0;
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 13 AND T_RILEV = 1;
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 16 AND T_RILEV = 2;
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 19 AND T_RILEV = 3;
```

where the field T_RILEV represents the evaluation time. In words the above queries allow to select the following children:

- those ones having started the program at the age of 10 months;
- those ones having started the program at the age of 7 months;
- those ones having started the program at the age of 4 months;

at specific evaluation times T_0, T_1, T_2, T_3. In Figure 5, there is the comparison between the development trajectory of a child without disabilities (ideal trajectory) and the measured one.

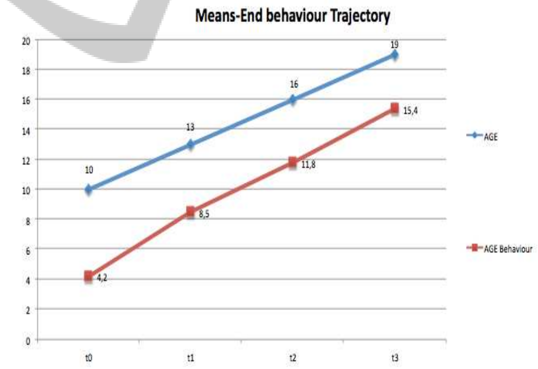

Figure 5: A comparison between the ideal development trajectory and the measured one. The ordinate axis gives the development age.

Then, by means of the following query:

```
SELECT AVG (ES) FROM CURRICULUM
   WHERE AGE = 10 AND T_RILEV = 1;
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 13 AND T_RILEV = 2;
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 16 AND T_RILEV = 3;
SELECT AVG (ES) FROM CURRICULUM
  WHERE AGE = 19 AND T_RILEV = 4;
```

we select both children having the age of 10 months at time T_0 or T_1. Similarly, we select by means of a query both children having the age of 10 months at time T_0 or T_2 As it is shown in Figure 6, the development trajectory of the children that have been unrolled under the curriculum for more time, it is much more close to that one related to those children that have been unrolled under the curriculum from less time. This at any fixed age.

Figure 6: Comparison between development trajectory of children unrolled under the curriculum for different time. The ordinate axis give the development age.

4.2 Analysis of the Development Rate

On a real sampling of 12 patients enrolled under the Carolina Curriculum, we select information about the development rate automatically calculated by the software.

Table 1: Development Rate.

	10 months	13 months	16 months	19 months
T_0	25.2	34.3	44.5	55,7
T_1	45.1	49.3	55.4	62.3
T_2	54.3	58.8	63.6	67.1

The values are normalized to 100. Observe that the more the children are enrolled under the curriculum the more the development rate get closer to the ideal development rate.

5 CONCLUSIONS

In this work, we have reported a study for the design and the development of an information system software based on client-server application for the implementation of the Carolina Curriculum for children with special needs. This Curriculum concerns the continuous collection of several dishomogeneous data and its analysis to set-up an appropriate program for the skill development of children with special needs. In particular these data are the bottle-neck in the practical application of the Carolina Curriculum due to the concurrent management of evaluation tables, scores, development indicators, etc. The software we have implemented solves this problem by means of a user-friendly web application in which the operator by means of a modular structure, can add, modify, delete, recover patient data as well as to show aggregate data via charts. These operations are all required by the Carolina Curriculum. Moreover, the software offers a comparison among data that is unthinkable using Carolina Curriculum by hands. In particular, by means of a clinical application, it has been possible to show interesting properties over the patients treatment: “the more the children have been unrolled under the curriculum the more their behavior is closed to a standard one”. This property is important not only from its one, but also to set-up the ability of our software to be an useful tool for future medical research.

ACKNOWLEDGEMENTS

We thank Professor E. Del Giudice of Department of Pediatrics for the data he gave us for testing our software. We also thank Dott. A. Olivo for useful discussions on the Carolina Curriculum, on which she is an expert, and for her practical advices on developing the software.

REFERENCES

E. Bates, L. Benigni, I. B. L. C. V. V. (1979a). *The emergence of symbols: cognition and communication in infancy*. New York: Academic Press.

E. Bates, L. Benigni, I. B. L. C. V. V. (1979b). Perceptual aspects of tool use in infancy. In *Infant Behavior and Development, 34*, pages 127 – 140.

E. Del Giudice, L. Titomanlio, G. B. A. B. A. R. G. M. R. P. O. D. M. E. T. G. A. (2006). Early intervention for children with down syndrome in southern italy: The role of parent-implemented developmental training. *Infants and Young Children*, 19:1:50–58.

M. Nancy, Johnson-Martin, S. M. A. B. J. H. (2004). *The Carolina Curriculum for Infants and Toddlers With Special Needs*. Paul H. Brookes Pub Co., 3rd edition.

Piaget, J. (1953). *The origin of intelligence in the child*. London: Routledge and Kegan Paul.

R. S. Chapman, L. J. H. (2000). Behavioral phenotype of individuals with down syndrome. *Mental Retard. Developm. Disabil. Res.*, Rev. 6:84–95.

S. Bruce, C. Campbell, M. S. (2009). Supporting children with severe disabilities to achieve means-end. *TEACHING Exceptional Children Plus*, 6:1:1–15.

Woodward, W. M. (1971). *The development of behaviour*. Harmondsworth, England: Penguin.