ECIDS: Standardizing the Data for Birth to 3 Programs
Kaycee McClyman1, Timothy B. Patrick, PhD2, Paula M. Rhyner, PhD1
1Department of Communication Sciences and Disorders and 2Department of Health Sciences, University of Wisconsin-Milwaukee

Abstract
There is a compelling need for standardized coding schemes to represent data collected for children receiving services through Milwaukee County early intervention (Birth to 3) programs. We are standardizing Birth to 3 data in our ongoing development of the Early Childhood Integrated Database System. Our efforts balance the need for individualized service plans with the need for aggregate analysis.

Background
In this poster we describe and motivate our preliminary approach to standardizing the data collected for developmentally disabled children receiving services through Milwaukee County early intervention (Birth to 3) programs. Developmental disabilities are prevalent and among the most costly conditions affecting children and adults in the United States. [1] Referrals to Milwaukee County’s Birth to 3 programs tripled from 1990 to 1999. [2] Young children with disabilities in Milwaukee County receive Birth to 3 assessment and intervention services from various providers, including hospitals, community agencies and local education agencies. Child information is collected on an as-needed basis as unstructured text. Standardized coding schemes for the representation of Birth to 3 services data are needed to allow examination of data in aggregate form for reporting, surveillance, and quality measurement purposes.

Balancing Individualized Intervention with the Need for Aggregate Analysis
Attempts to standardize Birth to 3 data must take into account Federal regulations that require interventions and service plans to be individualized for each child. [3] For example, consider the following intervention goals:

“Child A will attend to, and comprehend various durations of sounds (e.g., making a toy cat jump up for short, staccato sounds, and making it glide across the floor for long sound) within a group (e.g. family, childcare, etc.) environment.”

“Child B will participate, verbally and/or non-verbally, within family activities, as measured by parent/clinician observations and behavior checklists.”

“Child C will comply with age-appropriate rules, limits and routines (e.g. familiar routines; common boundaries of daily living) with fading prompts/models from parents.”

As written, these goal statements satisfy the need for individualized services and interventions. Yet they may constitute a barrier to analysis of trends since, even though they are certainly similar in content, they are not obviously comparable. If, however, they were associated with a broader standard code, such as “The child will increase appropriate social interactions and behaviors within familiar routines and with familiar partners”, the data could be analyzed for outcomes and trends in the aggregate.

The ECIDS Project
Our Birth to 3 data standardization efforts, which are ongoing, are part of our development of the Early Childhood Integrated Database System (ECIDS) [4]. Our method is to determine the statistical significance of the frequency of occurrence and co-occurrence of expressions of important data values in a representative sample of Birth to 3 child information. Following this analysis we use standard vocabulary construction techniques to develop the standard code sets for Birth to 3 child information. To insure that the development represents a consensus among stakeholders in the Birth to 3 services community, we will solicit comments and suggestions throughout the development process.

References