

Behavior Scale Can Help Clinicians

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First and foremost, I thank all of the CdLS families who participated in this study. If you were one of the 179 families that filled out a series of “endless” questionnaires about your child’s behavior problems at one of the CdLS conferences or online, the fruits of your labor resulted in the publication of *Behavior Problems in Individuals with Cornelia de Lange Syndrome: Population Specific Validation of the Behavior Problem Inventory*.*

The Behavior Problem Inventory** is a rating scale that assesses the frequency and severity stereotypic (stereotypy, repetitive behavior, etc.), aggressive, and self-injurious behaviors. It contains a list of 51 challenging behaviors often observed in individuals with intellectual disabilities.

Clinicians and researchers use rating scales as a way to quantify how big of a problem challenging behaviors are from the perspective of a parent, teacher, or other caregiver. This is a very important task because many individuals with CdLS have difficulties self-reporting these behaviors, and caregivers spend the most time with the individual and know the most about his/her challenging behaviors. Therefore, it is very important that we use a rating scale that we are quite confident will produce an accurate representation of the challenging behaviors from the caregivers’ perspective.

The BPI-01 has been shown to provide an accurate representation of challenging behavior for individuals with intellectual disabilities, but it has not been shown to produce accurate results for individuals with CdLS (along with all the other rating scales available to clinicians and researchers). The purpose of the study is to validate the BPI-01 specifically for individuals with CdLS. Without going into the technical aspects of the statistical analyses, I am happy to report that the BPI-01 is appropriate to use for measuring challenging behaviors exhibited by individuals with CdLS.

One critique of the BPI-01 is that it may not list all challenging behaviors exhibited by an individual with CdLS but this limitation is handled via an “other” line that allows the reporter to write down any challenging behavior and rate it on frequency and severity.

The big advantage of knowing that the BPI-01 is appropriate to use with CdLS is that it provides assurance to clinicians that the BPI-01 is a good measure of challenging behavior to use with individuals with CdLS. It



also sets the occasion for CdLS researchers to incorporate the BPI-01 into their studies so they can more easily compare and aggregate results on challenging behavior in CdLS across studies. These two advantages may result in better clinical assessment and monitoring of treatments for challenging behavior, and help us more clearly study how these challenging behaviors develop and maybe, eventually prevent some forms of these behaviors in CdLS.

In closing, we thank the CdLS Foundation for providing a grant to partially support the cost of completing this study. I am truly amazed each and every time I interact with the CdLS Foundation staff. I wish each genetic disorder foundation was equally well organized and careful with how they continually attempt to help those with CdLS in need, along with funding research that will hopefully help individuals with CdLS live a better life.

**Rojahn, Barnard---Brak, Richman, Dotson, Medioros, Wei, & Abby, 2013.*

***The Behavior Problem Inventory---01 (BPI---01; Rojahn et al. 2001)*

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