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Measuring Complexity for Autism Interventions: TCFD's Inventory of Neuroeducational Complexity

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Abstract

Autism is a complex condition, whether viewed from etiology, comorbidities, functioning, or interventions. There are numerous approaches for measuring complexity in children and adolescents with neurodevelopmental or medical diagnoses. Interventions, however, create the need for broader and deeper assessment—including the environments in which the young person lives. The Center for Discovery, New York state's Center of Excellence for Developmental Disabilities, (TCFD) implemented an Assessment, Support, Education and Training (ASSET) grant from the New York Office for People with Developmental Disabilities. This paper will describe the Assessment activity. A major goal was to develop a tool for assessing the characteristics of the young person and pivotal environments. The objective was to promote the delay of or prevent movement to a more restrictive placement including residential placement. The pilot tool was developed over nine months and includes six areas for evaluation—medical/impairments (8 items), functional profile (11 items), educational profile (5 items), home/family environment (9 items), school environment (6 items), and community environment (4 items). Implementation of CfD's Inventory of Neuro-educational Complexity (INC) was able to distinguish among 30 pilot subjects those likely to use family and school interventions to maintain family living from those most likely needing at least short term residential placement. The INC is of substantial heuristic value in this time of great interest in effective and resource-focused interventions with this population.

Keywords: Autism; Disorders; Child care; Developmental disabilities

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Introduction

Autism has become the dominant developmental disability in both health and education. The current prevalence statistics from the US Centers for Disease Control and Prevention indicate 1 of 68 children is living with this condition [1]. The rapid increase in the number of children has been variously assigned to better diagnosis, parental factors, genetics, and environmental influences, to name a few. With the increase in recognition has come focused attention on interventions? The diagnosis of autism, however, tells little of the spectrum of characteristics experienced by any one young person with the diagnosis. Functional differences among young people may be greater within the autism diagnostic group than between autism and other diagnoses, for example learning disabilities. Young people identified with autism show substantial and varied functional difficulties. Lollar et al. [2]. presented data analyzing the National Survey for Children with Special Health Care Needs. The results indicated that parents of children and youth identified with autism report significant difficulties of their children with behavior problems (58%), difficulty making and keeping friends (71%), difficulty speaking communicating or being understood (80%), and feeling anxious or depressed (67%). Among 16 common childhood health conditions including autism, this profile of functional difficulties for the population of children with autism was ranked first or second in prevalence—first for behavior and friendship and second for communication and anxiety/depression. Ninety one percent of parents reported their children had difficulty learning, understanding, or paying attention, while 56% had difficulty with self-care such as eating, dressing, and bathing. This profile of functional difficulties suggests that this population exhibits a substantial array of problems, beyond just those usually associated with autism-communication, social skills, and behavior.

Alongside the variety of functional issues have come significant differences in treatment interventions-from Applied Behavior Analysis (ABA) (Journal of Applied Behavior Analysis) to developmental approaches, including therapeutic floor time and health-focused developmentally-appropriate interventions [3]. Across all of these issues—etiology, functioning, treatments [4]—there is at least one common theme—complexity.

"Complexity" is the term that communicates the breadth and depth of characteristics experienced by the young person and their family. The term also allows us to move beyond just level of severity of a symptom, behavior or attitude, and can accommodate the influence of the family, school, and community environments in the initiation, development, and maintenance, of perceptions, behaviors, and emotions, as well as a factor in therapeutic interventions. Medical complexity has been a growing part of pediatrics for several years. Kuhlthau [5] synthesized the work of a group of more than 30 prominent pediatric clinicians and public health researchers, providing an overview of the various tools developed to measure complexity, mostly in in-patient settings. Kuhlthau suggested the 12 tools could be divided into four major groups, using the following: 1) A grid approach (e.g., illness or condition in rows with metrics, such as length of time expected to last in the columns). Carol Lilly uniquely addressed social, family, and community resources in her grid approach; 2) A tier approach, using characteristics such as chronic disease lasting more than one year and involving multiple organ systems in one tier, chronic disease lasting greater than one year, but involving one system as a second, and no disease greater than one year; 3) A yes/no approach, for example, using questions from the Children with Special Health Care Needs Screener; 4) a category using descriptive responses focused on specific areas included in complexity, such as the need for an interpreter. David Bergman, in this latter category, addressed the need to consider the purpose or use of a classification system for complexity. If decisions about which services a family or young person is to receive, then the system should be easy to use, flexible, and used at the place where care will be provided. If outcome research is the goal, including different sites and populations, then administrative data with clearly defined variables should be used. Rishi Agrawal asked "How do we fashion a system that covers a wide range of complexity levels?"

This exercise clearly indicated the need for addressing the issue of complexity relative to issues such as eligibility for medical and clinical programs, intensity of care elements, and research.

The New York Office for People with Developmental Disabilities (OPWDD) provided a grant to the Center for Discovery entitled Assessment, Support, Education and Training (ASSET) that specifically focused on children and adolescents who had been identified with autism through their county OPWDD offices or school system. A major goal of the grant was to assess the referred young people using standardized tools in speech, physical therapy, occupational therapy, psychology, behavior analysis, medicine, and nursing. The evaluations would also include developing a tool to collect information on the environments in which the children and adolescents currently lived their lives that is home, school, and community. This multi-source data would then be compiled and synthesized by the assessment team to develop a complexity profile for each referral. This profile would be used to suggest whether home/school intervention could prevent referral to a long-term residential treatment center, thereby increasing family unity and reducing state and federal Medicaid funds for interventions. A second major goal was to use a 10 week intervention period with parents and teachers in the home and school to identify and modify behaviors assessed as priorities. This article will address the first of these goals—development of the Inventory of Neuro-educational Complexity (INC).

Methodology

Procedures/Multisource data development and compilation

Before the evaluations were completed, the TCFD program and research team decided on several foundational assumptions. First, "complexity" includes characteristics of the young person identified as "autistic". Second, family characteristics and dynamics may substantively affect the young person's functioning. Third, the home, school, and community environments significantly influence the young person's adaptation, attitudes, and behavior. Fourth, the tool should include these elements, but focusing on the most powerful variables from each dimension, ending with a minimal data set of information.

The Center's leadership was in daily contact with the ASSET Program leadership team to review progress on gathering and analyzing behavioral and physiological data identifying efficacious interventions and developing eligibility criteria. Data and information collected through assessment was used by staff to create appropriate metrics for each of the variables included in the INC. Because the students and families involved in the ASSET program were an extremely diverse group of individuals with autism in need of support, staff and leadership continued the process of identifying appropriate elements of complexity and the associated metrics over a nine-month period.

Typically with regards to ASD, there is focus on the measurement of a young person's abilities across specific domains. However, without a broader understanding of etiology, interventions that may have greatest impact are lost. In the service of understanding the individual, a whole-body, whole-environment system was necessary. Beginning with a broad review of medical limitations, we then explored the child's ability to function. Most critically, our conversation of complexity acknowledged the need to understand the environment just as fully as we understand the child. Conventional approaches restrict focus to the individual, but understanding the goodness-of-fit of the environment is essential in finding the most effective ways to support the children and families. Combining expert knowledge of disability assessment with decades of clinical experience with Autism Spectrum Disorders (ASD), the current INC framework consists of six primary domains: medical impairments; general function; function in an educational setting; the home and family environment; the school; and the local community.

With the six domains identified, we began work to identify multiple sub-items to capture complexity within those domains. These decisions were informed by literature reviews, consultations with medical and educational leadership, and clinical observation. Sub-items emerged from this conversation and continue to be reviewed. For example, medical impairments sub-items include co-occurring conditions and comorbid diagnoses, as well as hospitalizations and medications. Functional reviews of the individual in daily life and school settings involve tools to assess, among many others, daily living skills, communication and behavior in school settings. Environmental domains assessed multiple aspects across the home, school and in the local community. Some of these sub-items include autism-related stress in parents, family cohesion, resiliency, and ability to access services, accessibility of services in the community, school administrative support, and ability of staff to implement programming to the student in question.

After the basic infrastructure of the INC was established, ASSET staff and leadership worked to define values for each category of the INC. As each category of the INC covered wide ranges of abilities and qualities, time was dedicated to defining each construct and identifying an appropriate starting point for scoring ranges. Where appropriate measures were already available, we relied on those established tools (e.g., the Vineland Adaptive Behavior Scale (VABS), Family Cohesion scale, and Brief Resilience Scale) to increase overall objectivity and to reduce bias in scoring. Developing a scoring mechanism for each factor allowed us to generate a quantitative value for each element and domain that eventually, when regarded carefully and with context, could assist in the process to decide the most effective service settings for individuals and their families.

Additionally, the ASSET team conducted ongoing reviews of items to insure that all components were consistent with the standard for disability classification--the International Classification of Function, Disability, and Health--Children and Youth (ICF-CY) [6]. This is a comprehensive framework for actual coding of both child and environmental variables impacting function and participation. We also reviewed the Supports Intensity Scale for Children (SIS), which includes multiple environments surrounding a child and assesses the degree of support necessary for success in each.

Each revision to the INC generated an additional workflow during the nine months of development. Once a construct was operationalized, we identified the data source and best way to measure it (e.g., by formal assessment, self-report, or direct observation), established a gradient of scoring aligning with degree of complexity in that construct, and modified the workflow to ensure the data were collected. As the INC was being revised, an INC Scoring Guide was drafted as an initial step in training those on the ASSET team who would assist with scoring exercises. External experts provided ongoing review, feedback and assistance in the process, which resulted in a draft of the INC that could be used for initial scoring of a subset of the ASSET participants.

Instrument status

The TCFD Inventory of Neurodevelopmental Complexity consists of 6 domains, as indicated previously. **Table 1** provides the inventory of domains and elements within each domain.

Scoring of each element was from 0 indicating little or no contribution to complexity to a scaled score of 4, associated with substantial complexity of the young person and/or their environment. The metric for each element was initially developed by the research team, and then revised as data was collected and analyzed. As decisions were made about each element, nuances such as distinguishing medical from psychiatric visits, medications, and hospital stays were important. Functional profiles depended more on existing tools, such as the Vineland Social Maturity Scale, along with secondary conditions collected from reports by parents, and the use of assistive technology. Educational functioning included nuances such as the stability of placement and peer interactions. Equally important, however, was determining the degree to which home, school, and community environments were facilitators or barriers to participation in daily activities. In addition to concerns about abuse or neglect and caregiving stress, issues such as time, effort, and cost to access services and the capacity to utilize technology for home support were included. The school environment was evaluated for administrative cooperation (getting access to a school for ASSET staff) to capacity of staff to adopt and implement programs were included. Finally, community resource availability was assessed, including transitions services for the adolescent population.

Table 2 provides correlation coefficients using Spearman's rho among the six domains and with the total complexity score. The data show several significant relationships. Each of the six domain scores correlate significantly with the total complexity score, suggesting convergent validity of the concept of complexity in the INC tool with this pilot sample. This is important in order to initially validate the use of the tool for the subsequent sample distinctions based on levels of complexity. In addition, the person-oriented domains, i.e., medical/impairments, functional profile, and educational profile are significantly correlated, and the environmental domains, i.e., home/family, school, and community environments are also significantly correlated. This outcome suggests validity to the notion that environments and personal domains are conceptually and statistically distinct.

Subjects

One hundred thirty three young people were referred to the ASSET program and 101 were enrolled and served by the program. Not all data was completed for all enrollees so that the data analysis

Table 1 Center for discovery's inventory of neuro-educational complexity domains and elements.

Domain	Elements
1. Medical/impairments (#)	Co morbid psychiatric diagnoses • Comorbid non-psychiatric diagnoses • Evaluation-identified health conditions • Emergency room visits • Hospital stays—medical • Hospital stays—psychiatric • Medications—medical • Medications—psychiatric • Therapy disciplines
2. Functional Profile	Health conditions impacting function (parent report) • Overall Adaptive Behavior • Receptive communication • Expressive communication • Personal daily living skill Domestic daily living skills • Community participation • Interpersonal relationships • Coping • Degree of supervision • Adaptive technology (AAC, etc.)
3. Educational Profile	Current educational setting supports • Stability of placements • School progress • School behavior • Peer interactions at school
4. Home/family Environment	Family resilience Family cohesion Parenting stress Time, effort, cost to access services Perceived relationship with school Capacity to utilize technology for home support Caregiving strain
5. School Environment	Administrative cooperation Capacity of staff to adopt and implement programs Capacity to utilize technology to support student Perceived school relationship with family Travel support Transition plan (adolescents)
6. Community Environment	Social services • Mental Health Services • DDRO services • Transition services

for the placement projections included 30 of the enrollees. Independent staff members not involved in the evaluation of the young people assigned each of the 30 participants into one of three groups—less complex, more complex, and most complex—based on clinical observation. The INC had been previously completed for each of the 30 participants. **Table 3** provides basic demographic data for the 30 participants in the analysis.

Results

The demographics of the young people with an autism diagnosis in the three groups shows the usual extreme ratio favoring males to females—28 males and 2 females. In addition, the three groups show the trend toward more complexity with age. Also, those most likely to be in a residential facility and most complex

Table 2 Correlation coefficient matrix: Domain totals and total complexity score (*p<0.05; **p<0.01).

Domain	Medical	Function	Education	Family	School	Communication	Total
Medical	1.0	-	-	-	-	-	-
Function	0.40*	1.0	-	-	-	-	-
Education	0.32	0.41*	1.0	-	-	-	-
Family	0.21	0.09	0.19	1.0	-	-	-
School	0.10	0.21	0.01	0.44*	1.0	-	-
Communication	-0.02	0.11	0.34	0.59**	0.13	1.0	-
Total	0.47**	0.71**	0.59**	0.65**	0.43*	0.57**	1.0

Table 3 Level of complexity by mean age and sex distribution.

Level of Complexity	Age	Sex Distribution
Least complex (n=11)	10.7 years	10 males, 1 female
More complex (n=11)	12.2 years	9 males, 1 female
Most complex (n=8)	14.4 years	8 males

are substantially older than those less complex and more likely to have home and school interventions that may be less effective.

In each of the six domains of the INC, there is a difference between the scores of the less and most complex young people. In all but one domain, the scores of the more complex fall between the less and most complex groups. The school environment domain showed the only exception to this pattern, perhaps related to the most complex group's reduced involvement with school systems in their community.

Table 4 presents the differences among the three groups. The Analysis of Variance (ANOVA) statistic shows no significant difference in medical complexity across the groups. Functional difficulties, however, are shown to be significantly different across groups (p<0.05). Educational differences related to the young person's behavior, progress, and stability were also significantly different across the levels of complexity (p<0.003). Environmental factors did not contribute to the complexity differences as was hypothesized for this pilot sample. To clarify among which complexity groups the significant differences occurred, a Scheffe's test of multiple comparisons was implemented for the two significant domains—functional and educational profiles. Results showed a borderline significant difference (p<0.052) between the less and most complex groups for the functional profile domain. For the educational profile domain, the less complex group had significantly lower scores, indicating fewer school-related issues, than either the more complex (p<0.025) and the most complex group (p<0.005).

In the intervention section of the ASSET grant (not part of this article), it was found that the young people in the most complex group were most likely to profit from residential intervention, while those in the group with more complexity could profit from a short-term residential experience. The least complex group was projected to profit from home/school/community interventions.

Discussion

The development of a pilot tool to assess complexity in children and adolescents diagnosed with autism along with relevant environmental elements produced positive outcomes. Using a conceptual framework, the World Health Organization's International Classification of Functioning, Disability and Health [6] gave both comfort and promise that major areas of impairments, activity limitations, participation, and environment were included. ASSET leadership and staff experienced in autism assessment and intervention, worked to trial the INC across a sample of students and their families and compare against how the families and individuals responded to our services. This was a critical first step–to study whether the factors identified as being important to complexity within the tool align with what is known clinically to be important for the success of children and their families. Scores provide a foundation for future intervention planning within complexity to highlight areas of need. It was also important as a way to examine the helpfulness of scoring distributions for the major factors and their constituent sub-items, i.e., do higher scores adequately capture complexity? Also, do some factors or sub-items capture it more efficiently? Can the INC be revised to provide strength to placement decisions for local and state agencies?

Results show that educational factors play a large role in perceptions of the complexity of the young person living with autism. It is without doubt that the behavioral and interpersonal difficulties of the children and adolescents contribute significantly to parents and teachers deciding to seek more intensive therapeutic interventions, including residential treatment that often extends for years.

Another conclusion from this pilot data is that functional abilities are relatively more important than medical conditions, comorbidities, or even psychiatric conditions in measuring complexity. This would not suggest that the medical/psychiatric conditions are unimportant. Of course, medical conditions can affect functional abilities. Results, however, indicate that functional abilities are an extremely important set of characteristics when assessing complexity. This would then lead to a more serious consideration of functioning when interventions are being considered. An example of this is the case of a 15 year old ready for referral to residential placement as the project began.

K presented with significant self-injury, hitting head with hands, fists or knee, and anxiety significant enough to preclude a

Table 4 Analysis of variance: Complexity group by complexity domain.

Complexity Domain		Sum of Squares	df	Mean Square	F	Sig.
Medical/Impairments	Between Groups	12.819	2	6.409	0.337	0.717
	Within Groups	514.148	27	19.043	-	
	Total	526.967	29	-	-	-
Functional Profile	Between Groups	380.155	2	190.077	3.344	0.050
	Within Groups	1534.545	27	56.835	-	
	Total	1914.700	29	-	-	-
Educational Profile	Between Groups	103.643	2	51.822	7.480	0.003
	Within Groups	187.057	27	6.928	-	
	Total	290.700	29	-	-	-
Home/Family Environment	Between Groups	21.285	2	10.642	0.614	0.548
	Within Groups	467.682	27	17.322	-	
	Total	488.967	29	-	-	-
School Environment	Between Groups	17.285	2	8.642	0.351	0.707
	Within Groups	665.682	27	24.655	-	
	Total	682.967	29	-	-	-
Community Environment	Between Groups	58.730	2	29.365	1.281	0.294
	Within Groups	619.136	27	22.931	-	
	Total	677.867	29	-	-	-
Grand TOTAL	Between Groups	1689.912	2	844.956	2.613	0.092
	Within Groups	8731.455	27	323.387	-	
	Total	10421.367	29	-	-	-

complete multidisciplinary evaluation. He had not attended school for 2 months and had to be monitored constantly both awake and asleep. He rarely left home and required such intense supports that his father had lost his job and was the primary caregiver. The family suspected some dental issues that contributed to his self-injurious behaviors. After evaluation, the TCFD team recommended physician referral to rule out medical issues and obtained a prescription for a soft helmet to alleviate bruising due to the Self-Injurious Behavior (SIB). The family was assigned to the training and education portion of the ASSET project, and home visits were initiated with the family. As a result, K's anxiety decreases sufficiently that he was able to return to school. He can now go for walks in the neighborhood and accessing enjoyable activities that preceded the SIB. As of the final visit in the school setting, K was able to wear his soft helmet successfully for a period of time, and his circle of support is less anxious, rested, and more confident.

Limitations

Limitations of the study include the small sample size. Also, there is a need for further examination of psychometric properties of the INC. Some of the items require subjective judgment so that reliability must be closely monitored. In addition, scoring metrics need to be systematically reviewed and revised so that summary scoring does not mask individual differences. Finally, characteristics of the environments and scaling of those characteristics require additional attention since clinical experience suggests substantial impact on the intervention decisions, but the environmental domains were not significantly associated with the placement of the three groups B.

Conclusion

Limitations notwithstanding, with the average cost of residential placement estimated to be $200,000 per year per child, appropriate screening, evaluation, and intervention decisions are important. At this point there are not tools available that provide a broad-based approach to making decisions regarding appropriate interventions except through trial and error, even after evaluation. The INC is still in developmental stages, but is of substantial heuristic value in the establishment of systematic approaches to assessment for the purpose of intervention decisions with the young people living with autism and their families.

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