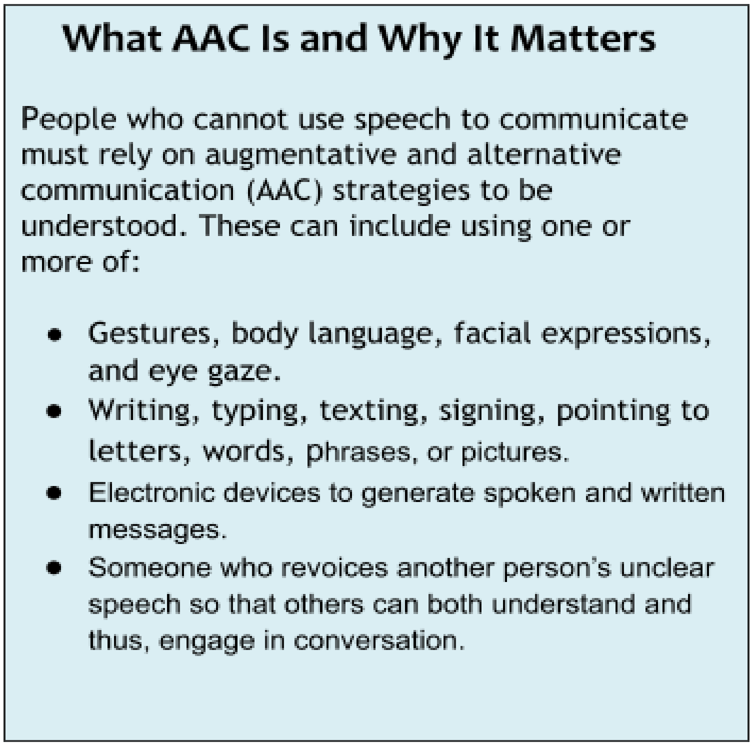
CommunicationFIRST
Because communication is a human right.

Written Testimony of Bob Williams, Policy Director of CommunicationFIRST, to the DC Council's Committee on Human Services
Re: B24-0268 - Developmental Disability Eligibility Reform Amendment Act of 2021
Friday, November 5, 2021

Submitted to: Nyasha Smith, Secretary to the Council, 1350 Pennsylvania Avenue, N.W., Suite 5, Washington, D.C. 20004; humanservices@dccouncil.us



What AAC Is and Why It Matters

People who cannot use speech to communicate must rely on augmentative and alternative communication (AAC) strategies to be understood. These can include using one or more of:

- Gestures, body language, facial expressions, and eye gaze.
- Writing, typing, texting, signing, pointing to letters, words, phrases, or pictures.
- Electronic devices to generate spoken and written messages.
- Someone who revoices another person's unclear speech so that others can both understand and thus, engage in conversation.

My name is Bob Williams. I am the Policy Director and a co-founder of CommunicationFIRST, the only national human and civil rights organization that is led by and advances the equal rights, opportunities, and dignity of the estimated five million children, women, and men in the U.S. who must use methods other than natural speech to express ourselves, to be understood, and lead our lives. These strategies and tools are referred to as augmentative and alternative communication or AAC (see box).

I also happen to be a DC resident and taxpayer. I went to George Washington University in the late 1970s and have lived and worked here for most of my life. I was born in the 1950s with cerebral palsy and the significant multiple communication, motoric, and physical disabilities that in my case accompany it. However, it is important to point out that my disabilities are not significant enough to be considered to be developmental disabilities as defined by the federal DD Act, the law I administered as the Commissioner of the U.S. Administration on Developmental Disabilities in the Clinton Administration.

We appreciate the opportunity to comment on the importance of the Developmental Disabilities Eligibility Reform Amendment Act of 2021 (DDERAA). **We believe the passage and effective implementation of the DDERAA will support the equal rights, opportunities, and fundamental humanity of all people with developmental disabilities in this city and help right an historic and continuing injustice.**

Between 1945 and 1967, parents of hundreds of thousands of children with actual or alleged intellectual and developmental disabilities were forced to put their sons and daughters into institutions. Despite horrid myths to the contrary, these parents did not do this out of malevolence or to abandon their child. They did so out of sheer desperation coupled with a great sense of guilt.

Harold and Betty Evans, like many parents, did their best to raise their daughter Joy at home but had to put her into Forest Haven when she was 8 because DC Public Schools and others throughout the nation deemed children like her as “uneducable” and uniformly barred them from the classroom. Harold and Betty, who I came to love and respect nearly as much as my own parents, never gave up on doing justice by Joy and all others at Forest Haven. Instead, they organized other parents to bring a class action with Joy as the lead named plaintiff that resulted in closing the institution and replacing it with a system of home and community based services.

Decades after Joy’s tragic death at Forest Haven, the Evans’ advocacy continued to be “like a tree standing by the water” – unbending and never ending. Listening to the parents who testified at the DC Council’s hearing reminded me with pride of Harold and Betty Evans and Bill and Bea Williams, my own parents. All these parents have ever demanded is simple justice for their sons and daughters to be treated fairly, to be educated, and to have the opportunities and supports they need to lead decent lives in community with all others.

I have been fortunate. Because our family was large, my parents were able to reject what was then the rote advice of physicians and most others to institutionalize me and never looked back. Instead, they raised me in the same rough and tumble world of strong love and expectations that my brothers, sisters, and I all grew up in. While I am no stranger to ableist bias, discrimination, and hate in my daily life, I have escaped its worst effects many baby boomers with significant disabilities faced growing up – and frankly many Millennials and Gen Zoomers with similar needs still face today. I realized early that there but for fortune, my family, hard work and, yes, White privilege, I had somehow evaded the egregious harm it still is doing to countless others.

This is what drove me to first get involved in advocating for my civil rights and the civil rights of other people with disabilities as a teenager in Connecticut and to continuously work on advancing the rights, opportunities, and supports for children, working age and older adults with significant disabilities. My career has involved closing Forest Haven, improving community living services in DC, helping to pass the Americans with Disabilities Act, and administering the federally funded developmental disabilities, Ticket to Work, and independent living networks. I am also developing a genealogical profile of those exiled to what was first called the District Training School for the Feeble Minded and later known as Forest Haven.

History has no redo’s. We can never completely undo the legacy of injustice. But if the last two years teaches anything, it is that we must learn and act on its lessons to forge greater equity for all. I offer this up because it informs my life and the work we do as an organization at CommunicationFIRST.

DDERAA is meant to do just this. CommunicationFIRST strongly calls for the swift passage of DDERAA into law as introduced by Councilmember Nadeau and seven other Councilmembers – a majority of the body. In doing so, we want to make clear that:

1. We believe the enactment of DDERAA is critical to advancing the equal rights and opportunities of all DC residents with the full range of developmental disabilities.

2. Its passage and effective implementation are essential for ending the pervasive discrimination that we know people with little to no understandable speech endure and cannot escape.

3. We strenuously urge its swift passage in its current form; and strongly oppose any attempt to weaken or entirely thwart its purpose and intended effects.

4. People with developmental disabilities living in DC who require but often lack access to robust communication supports to effectively express themselves, be understood, and thus, lead fuller lives are among those with the greatest to gain or lose from whether the DDERAA is enacted as written.

These are the reasons CommunicationFIRST calls on the Council to pass this landmark legislation this year and on Mayor Bowser to sign it into law and ensure her Administration carries it out in a manner consistent with its full letter and intent.

CommunicationFIRST publicly launched just six months before COVID-19 shut down much of the United States. As a result, much of our early work centered on blunting the pandemic's harsh effects on our community. We led a coalition of disability rights organizations to convince the HHS Office for Civil Rights to affirm the right of patients with disabilities to receive necessary in-person communication supports in hospitals despite hospital no-visitor policies. We also joined Disability Rights DC, Quality

Trust, and others to ensure that Washington MedStar fully complies with this requirement network-wide in DC.

More broadly, CommunicationFIRST seeks justice for all children, youth, working age and older persons with significant expressive disabilities regardless of race, disability or condition, language, gender identity, alleged IQ score, socioeconomic status, or any other characteristic or label. We do the work we do because, despite our diversity, we share a common oppression. The justice we seek must be shared, equitable, and universal to all. **The DDERAA is a vital tool for achieving justice and it can help spark similar change in other parts of our country.**

We Believe Justice Cannot Wait

Across the U.S. and the globe, people who require AAC and especially large numbers who need but lack effective access to robust AAC, are all too casually branded and treated as being "unintelligible," "nonverbal," and unquestionably "the other." We use a human and civil rights framework and set of tools to attack the dilemma we experience because the causes of it are deeply entrenched age-old bias, stereotype, and discrimination that must be exposed and ripped out root and branch.

To this day, many who require AAC endure the most egregious forms of bias, discrimination, and social death: unjustified isolation, institutionalization, illiteracy, illness, ostracism, abuse, violence, and social death. This leads, in effect, to individuals serving life sentences incommunicado, which in any other context and for anyone else would be rightly viewed and dealt with as a gross human rights violation.

Research further indicates that individuals who belong to racial, ethnic, and linguistic minority communities who need AAC face added difficulties in obtaining it. See here, here, and here.

Historically and to this day, such persons also are frequently wrongly assumed or wrongly "assessed" to have intellectual disabilities because they tend to have one or more behavioral, expressive communication, executive functioning, movement/motoric, sensory, or other disabilities that: a) mask their abilities and aptitudes; and/or b) result in them being mis-assessed by measures of intelligence precisely *because* they lack access to robust language-based AAC. Moreover, data from State DD agencies, including DC DDS, indicate that roughly one of every four adults (24%) receiving services from such systems express themselves with a method other than their natural speech. It is reported that over 80% of this group use gestures either primarily or exclusively to express themselves. Furthermore, the same data show black, indigenous, people of color, and those who do not speak English that are served by State DD agencies in the U.S. are more likely than their white peers to use primary means other than their speech to express themselves.

Standard IQ tests have 3 fatal flaws in assessing the intelligence of people unable to rely on speech alone to communicate:

1. Every IQ test assumes the test-taker can either answer questions reliably with speech or hand movements of their hands, something that many, if not most, of these individuals are unable to do.

2. IQ tests have not been normed on people with communication, sensory, or movement differences.

3. IQ scores are influenced significantly by racial, language, socio-economic, and cultural differences.

These shortcomings lead to damaging assumptions that people who score poorly on IQ tests are incapable of learning, communicating, and directing their own lives.

In many ways, these data points likely understate the magnitude of the problem because as a society, a field, and most importantly human beings, too many of us consciously or unconsciously believe that someone with little to no speech that most others can easily understand: a) has little ability, need, or right to say anything; and b) can just make do using what little residual speech, gesturing, and grunting they can muster to get through their the day and, indeed, their entire lives.

These statistics should be stark enough to shock us all to take action to afford everyone who requires AAC full and effective access to it. For the purposes of our comments on DDERAA, this must include all adults with developmental disabilities regardless of their reputed intelligence level.

In January, CommunicationFIRST was joined by 47 other organizations in calling on the Biden Administration to eliminate the discriminatory impacts that IQ assessments have on people with motor and speech disabilities. We have further called on the U.S. Department of Education and other federal agencies to identify and take effective short- and long-term actions to lessen their use and effects. See here and here. States and localities must take similar steps. Research indicates and CommunicationFIRST takes the position that these tools do not accurately measure the intelligence level of persons with developmental disabilities who lack both understandable speech and access to robust language based AAC. See Appendix I. Moreover, these inaccurate results actively cause harm to these individuals by leading others to judge them to be incapable of learning to use robust AAC. **CommunicationFIRST's position is that no entity or agency should use a standardized measure of intelligence on a person if they require but have been denied the supports needed to fluently access and use robust AAC.**

The continuing discriminatory effects IQ tests have on Black people, those with disabilities, English Language Learners and others serve as an additional red flag. These tests must be used only with great caution and circumspection. The demographics of our city and the fact that so many of our neighbors live at the intersections of race, disability, poverty, gender identity, as well as speak languages and come from cultures not well-understood by most in the government make it all the more imperative that we heed this warning.

We, therefore, strongly call on the District of Columbia and others to never make decisions affecting the lives of people who cannot rely on speech to be understood based on an IQ score. This is especially imperative for major decisions like determining eligibility for services as DC has done for well over a century.

The District is one of the few states that continues to rely exclusively on this biased and antiquated standard. Action to remedy this injustice is needed and long overdue.

We recognize that nothing in the DDERAA would bar DDS from using standardized IQ assessments when appropriate and we do not suggest any changes be made to the bill on this subject. We also do not view the DDERAA to be the total fix to the complex human rights crisis we are working to both shine a bright light on and engage governments at all levels to confront and address. However, we do believe the bill, if enacted as introduced, would spur progress in the right direction.

Ensuring that individuals with the full range of developmental disabilities are eligible for services and supports offered by DDS, regardless of their reported intelligence, is a human and civil rights imperative.

To be certain the last statement is not misinterpreted, let me be clear: DDERAA will not create an entitlement to DDS services for anyone. All it will do is make adults with support needs related to a developmental disability eligible for DDS regardless of their intelligence level. This in itself will go a long way towards eliminating one of the most fatal and still enduring parts of the District Training School for the Feeble Minded/Forest Haven legacy. Failure by the Council to pass a strong and clear version of the DDERAA or failure by the Executive to implement it in a transparent and trusted manner are an option. Its implementation must be continuously guided by people with developmental disabilities, their families, advocates, providers, as well as other stakeholders and thought leaders who look, sound, and are representative of those who live in all parts of DC.

When I monitored and assisted people to leave Forest Haven to live in DC more than a generation ago, everyone who had been exiled there shared the same label: “mental retardation.” To be sure, some of the people there that I came to know, love, learn from, and admire did have intellectual disabilities. But some did not. It was an open secret everyone knew – an administrative expedient everyone complicitly accepted because we assumed there was nothing that could be done about it. It was a moral failure by those of us, including me, who did little to nothing back then. It is one that continues to do great harm, and we must act to stop it.

Because this policy is still inexplicably in place, when individuals are found to have at least typical intelligence they are routinely denied access to the AAC and other supports they require to live in true community with others. Transition-age young people and adults with developmental disabilities including autism, cerebral palsy, Down Syndrome, Rett Syndrome, and rare, multiply disabling conditions are particularly likely to be denied access to AAC, regardless of whatever IQ label is permanently stamped on their body, spirit, and soul.

A decade ago, the DC Council lacked the political wisdom, morality, and will to enact legislation similar to your bill that I helped to write as the Senior Advisor to Judy Heumann, the first Director of DDS and a global leader on human and disability rights. A bill that Laura Nuss, who, as the second DDS Director, as well as a majority of the Council, including then-Councilmember Muriel Bowser, supported. For reasons that are elusive, however, its central provisions on making eligibility for DDS more equitable for DC residents with developmental disabilities regardless of an IQ score were never enacted.

The Council must not put this vital reform on indefinite hold ever again. As I said, the District has used the same standard to institutionalize people and much later to make them eligible for community living services, for over one hundred years. Currently, some adults with developmental disabilities are eligible for DDS community living services and others are not, and it all comes down to a two- or three-digit IQ score, which may or may not be accurate. This is plainly wrong. As the Council heard from public witnesses today, the intensity and multiplicity of support needs of an individual are not made less or greater based on IQ. Developmental disabilities can involve a range and combination of intellectual, behavioral, and physical support needs. If someone needs assistance in personal care, self-regulation or behavior, communication, living in the community, or employment, it is irrelevant what their alleged IQ score is. To claim otherwise is absurd and discriminatory, and fails to equitably meet the needs of DC residents with developmental disabilities based on an arbitrary, non-evidence-based number.

The Executive has budget and implementation concerns with the bill. And it should be given the tools to address those concerns. But the Council must not allow it to wield the carte-blanche power to kill the bill now or to eviscerate it when it is enacted. This is my major concern. And it must be yours as well. The current policy is blatantly unjust. The Council has the moral duty to make it right. A vote on it must be taken before next June's primary. We all must know who will and will not do what simple justice requires. Thank you.

APPENDIX I

Research on the Inappropriateness and Potential Harm of Using Standardized IQ Tests on Students with Motor and Communication Disabilities, Especially if they Lack Access to Effective and Robust Augmentative and Alternative Communication (AAC)

(compiled by CommunicationFIRST, 2021)

Cerebral Palsy

Foo, R.Y., Guppy, M., & Johnston, L.M. (2013), Intelligence assessments for children with cerebral palsy: a systematic review, *Developmental Medicine & Child Neurology*, 55(10): 911-918 (open access here)

Conclusion: Intelligence assessments in children with CP lack reliability data, consensus regarding validity data, and population-specific norms. Research is required to establish psychometrics for children with CP. For children with higher motor involvement and/or communication and/or visual impairments, multiple options are required to assess intelligence appropriately.

Key Quotations:

- “A major problem with establishing this diagnosis [of intellectual impairment], however, is that pediatric IQ assessments are generally developed for, and standardized with, typically developing children who do not have any physical impairments.”
- “Verbal IQ is useful when it is necessary to evaluate IQ in children with motor impairment as these subtests often do not include a motor component. Non-verbal IQ subscales measure a child's ability to reason without using words, which is generally measured using visual items such as symbols and pictures, for example solving a visual pattern.”
- “Despite the plethora of IQ assessments, it is difficult to identify those that both (1) report psychometric data for children with CP, and (2) suitably accommodate the heterogeneous range of impairments experienced by this population, in particular impairments of motor (100%), communication (60%), and/or visual function (37%). This is problematic because use of standardized IQ assessments that have been developed for the typical population can result in children with developmental disabilities receiving low IQ scores which are

not necessarily a true reflection of their cognitive abilities, but reflect the fact that physical impairments limit their performance on assessment items. It has been reported that up to 42% of children with special needs seen by preschool psychologists are not able to complete standardized IQ assessments. Inappropriate test selection should be avoided because it compromises population estimates of prevalence of IQ impairment. It can also significantly impair services provided for individual children. For example, where education systems use IQ to determine eligibility for service provision, an inaccurate result can affect access to education adjustment programmes, funding support, and placement within a mainstream or special school. In addition, inappropriate labelling of children as having an intellectual impairment may impact on the attitudes, expectations, and behaviour of the child and the people supporting the child, which may adversely affect access to opportunities and the child's future academic and career opportunities."

- "Standardization of IQ assessments for children with CP is so burdened by the heterogeneity of the population that no one assessment currently presents a fair assessment of all children. As all standardized assessments have been normed for children with typical physical development, they all include items that inadvertently penalize subgroups of children with CP, as a result of their motor, communication, and/or visual impairments. This may lead to questionable, possibly invalid, results. However, if any item is modified to make it more appropriate for a certain physical impairment, the item may lose standardization, again compromising the overall assessment validity."

Geytenbeek, J., Harlaar, L., Stam, M., Ket, H., Becher, J.G., Oostroms, K., & Vermeulen, R.J. (2010), Utility of language comprehension tests for unintelligible or non-speaking children with cerebral palsy: a systematic review, *Developmental Medicine & Child Neurology*, 52(12): e267-e277 (open access here)

Conclusion: Adequate and diagnostic tools specifically designed for the assessment of comprehension of spoken language of children with severe CP are not yet available.

Key Quotations:

- "Assessment of language comprehension skills becomes difficult because of problems with or absence of speech production, and uncertainty whether test failures are due to physical disability or limited intellectual and verbal comprehension abilities."
- "During the period of language development, children's comprehension skills not only precede but also exceed their productive language competency. Moreover, comprehension of spoken words (receptive vocabulary) and later sentences (receptive grammar) can develop even when the child is not speaking."

- "The utility of a test largely depends on its administration and reliable assessment."
- "Many standardized language tests require behavioural repertoires (such as oral answers, finger pointing, and object manipulation) that exceed the possibilities of children with moderate to severe motor impairment. Uncertainty can arise about whether test failures are due to limitations of mobility or due to limited abilities in language comprehension. Consequently, the use of standardized assessments may lead to an underestimation of the real comprehension abilities of the child."
- "The findings of this review underline that the PPVT-R is applicable in older children who are able to use direct selection methods and oral communication. However, it needs adaptations when used in young children with severe limited mobility and unintelligible or no speech, and/or in children with intellectual disabilities."
- "Non-standardized adjustments of test administration can limit the generalizing ability and validity of comparisons of groups to a standard. It seems that appropriate test measures and procedures specifically designed for young children with severely limited mobility are not yet available."

Ballester-Plané, J., Laporta-Hoyos, O., Macaya, A., Póo, P., Meléndez-Plumed, M., Vázquez, É., Delgado, I., Zubiaurre-Elorza, L., Narberhaus, A., Toro-Tamargo, E., Russi, M.E., Tenorio, V., Segarra, D., & Pueyo, R. (2016), Measuring intellectual ability in cerebral palsy: The comparison of three tests and their neuroimaging correlates, *Res Dev Disabil.*, 56:83-98 (paywall access here)

> Abstract: Standard intelligence scales require both verbal and manipulative responses, making it difficult to use in cerebral palsy and leading to underestimate their actual performance. This study aims to compare three intelligence tests suitable for the heterogeneity of cerebral palsy in order to identify which one(s) could be more appropriate to use. Forty-four subjects with bilateral dyskinetic cerebral palsy (26 male, mean age 23 years) conducted the Raven's Coloured Progressive Matrices (RCPM), the Peabody Picture Vocabulary Test-3rd (PPVT-III) and the Wechsler Nonverbal Scale of Ability (WNV). Furthermore, a comprehensive neuropsychological battery and magnetic resonance imaging were assessed. The results show that PPVT-III gives limited information on cognitive performance and brain correlates, getting lower intelligence quotient scores. The WNV provides similar outcomes as RCPM, but cases with severe motor impairment were unable to perform it. Finally, the RCPM gives more comprehensive information on cognitive performance, comprising not only visual but also verbal functions. It is also sensitive to the structural state of the brain, being related to basal ganglia, thalamus and white matter areas such as superior longitudinal fasciculus. So, the RCPM may be considered a standardized easy-to-administer tool with great potential in both clinical and research fields of bilateral cerebral palsy.

Deafness & Hearing Disabilities

Reesman, J.H., Day, L.A., Szymanski, C.A., Hughes-Wheatland, R., Witkin, G.A., Kalback, S.R., & Brice, P.J. (2014), Review of intellectual assessment measures for children who are deaf or hard of hearing, *Rehabilitation Psychology*, *59*(1), 99-106 (paywall access here)

> Abstract: Intellectual assessment of children who are deaf or hard of hearing presents unique challenges to the clinician charged with attempting to obtain an accurate representation of the child's skills. Selection of appropriate intellectual assessment instruments requires a working knowledge of the strengths and weaknesses of the measure and what changes in standardized administration might be necessary to accommodate for the needs of children who are deaf or hard of hearing. In the case of some available instruments, there is limited guidance and objective research available examining the performance of children who are deaf or hard of hearing. This review summarizes available information on widely used and most recent editions of intellectual assessment measures with special attention to guidance on accommodations, score interpretation, subtest selection and other test-specific considerations when assessing children who are deaf or hard of hearing. Summary: There is much opportunity for further inquiry in the field of intellectual assessment as it applies to children who are deaf or hard of hearing, as many measures have not been closely scrutinized for their appropriate use with this population. Clinicians must recognize inherent difficulties with intellectual assessment measures with children who are deaf or hard of hearing and issues in providing for an accessible and accurate administration of test items.

Illinois Service Resource Center (2011), *Guidelines for Psychological Testing of Deaf and Hard of Hearing Students* (open access here)

Key Quotations:

- "The use of standardized tests to determine the cognitive abilities, academic achievement, and mental status of people who are deaf or hard of hearing may result in inaccurate or misleading results. Few tests have been normed on deaf and hard of hearing populations. Comparison norms are made to English-speaking, same-age students without a hearing loss. Assessment results need to be considered and interpreted in this light. Misdiagnosis can follow an individual throughout his/her lifetime."
- "Inappropriate testing has, historically, resulted in deaf people frequently being misdiagnosed, frequently as mentally retarded. There are few formal training opportunities for psychologists to learn about assessing this population and become aware of the impact that deafness may have on reading levels, testing issues, use of interpreters, etc."

McCay, V. (2005), Fifty Years of Research on the Intelligence of Deaf and Hard-of-Hearing Children: A Review of Literature and Discussion of Implications, ***The Journal of Deaf Studies and Deaf Education*****, 10:3, 225-231 (open access** here**)**

> Abstract: In 1965, McCay Vernon drove a stake through the heart of the long-established "truth" that deaf people were inferior to hearing people. Launched by Aristotle, emboldened by the 1880 Conference of Milan, and reiterated in the twentieth century through the biased research of many psychologists, this falsehood persisted until the publication of this classic review paper. Vernon succinctly spotlights biases in IQ assessment of deaf children resulting from improper testing methods, research participant sampling, even the experience level of the evaluators themselves. Brief and scholarly, the paper had enormous impact not only on future research regarding cognition and deaf people but on clinical practice as well. Within this paper, insights are evident which Vernon has continued to elucidate throughout his long career. He was arguably the first psychologist to view the deaf population as a heterogeneous one, noting how various hearing loss etiologies differentially affect cognition and other psychological characteristics. His later research, notably that which focused on rubella, deafblind, and deaf forensic populations, has been similarly pioneering. McCay Vernon's extensive professional impact stems not only from his prolific, readily applied research work but also from his generous and vigorous activities as a teacher, a mentor, and advisor. – Robert Q. Pollard, Jr.

Deaf-Blindness

U.S. Office of Special Education Programs (2009), "Assessing Communication and Learning in Young Children Who Are DeafBlind or Who Have Multiple Disabilities," available here

Key Quotations:

- "An IQ score does not accurately describe the cognitive abilities or potential of a child who is deafblind. Such tests are highly dependent on verbal and perceptual skills and seem almost designed to assure poor performance from children who are deafblind. While state and local regulations may require that standardized measures be administered, they are unlikely to provide information useful in program planning or in predicting outcomes for children who are deafblind or who have multiple disabilities."
- "The most important assessment goal is to gain an understanding of the child's real-life skills and concepts as applied in educational, home, and social settings. It is less critical to obtain "scores" such as age equivalencies or IQs, which are unlikely to be either valid or helpful."

National Association of State Directors of Special Education (2018), *Optimizing Outcomes for Students who are Deaf or Hard of Hearing: Educational Service Guidelines* (open access here)

Key Quotations:

- "Few assessment instruments are designed to specifically target the needs of children who are deaf or hard of hearing, which means that all assessment results must be considered with caution. Often, communication barriers exist and the evaluator cannot reliably determine the student's cognitive, social and functional capabilities. The evaluation process can be frustrating to both the student and the evaluator if only standardized assessments are used. Results of the assessment, such as standard scores, IQ, or age equivalents, may mask a person's true skills and competencies."
- "It is important to note that standardized tests applied to special populations, such as deaf or hard of hearing students, may not be entirely valid. Assumptions about English language proficiency with test constructs and interpreted assessments, which may rely on content proficiency of the interpreters or diagnosticians, are just a few of the challenges of test validity when assessing students who are deaf or hard of hearing. In addition, a students' lack of experience in performing self-ratings can affect the validity and reliability of transition test results."

Mar, H. (2010), *Psychological Evaluation of Children Who Are Deaf-Blind: An Overview with Recommendations for Practice*, National Consortium on Deaf-Blindness (open access here)

Key Quotations:

- "Evaluation of students who are deaf-blind is a challenge to all concerned. From the psychologist's point of view, there are few professional standards to go by. Most psychological tests are inappropriate because they have been developed for students with normal vision and hearing. Often, communication barriers exist and the psychologist cannot reliably determine the student's cognitive, social, and functional capabilities. From the student's point of view, the evaluation process can be frustrating if the tasks are not meaningful and if the materials cannot be easily perceived. For the educator and parents, test scores, such as age levels or IQs, can mask a person's true skills and competencies. Assessment reports may not provide an accurate profile of a student, and may not provide information that will be helpful."
- "Scores may not be valid once there is departure from standard procedures; they may underestimate or overestimate an individual's true potential. But more important, adaptations may be appropriate only if using the test is relevant in the first place, that is, if the test measures the types of skills that correspond to the student's educational goals and school experiences."

Autism

Dawson, M., Soulières, I., Gernsbacher, M.A., & Mottron, L. (2007), The Level and Nature of Autistic Intelligence, *Psychological Science*, 18:8, 657-662 (open access here)

> Abstract: Autistics are presumed to be characterized by cognitive impairment, and their cognitive strengths (e.g., in Block Design performance) are frequently interpreted as low-level by-products of high-level deficits, not as direct manifestations of intelligence. Recent attempts to identify the neuroanatomical and neurofunctional signature of autism have been positioned on this universal, but untested, assumption. We therefore assessed a broad sample of 38 autistic children on the preeminent test of fluid intelligence, Raven's Progressive Matrices. Their scores were, on average, 30 percentile points, and in some cases more than 70 percentile points, higher than their scores on the Wechsler scales of intelligence. Typically developing control children showed no such discrepancy, and a similar contrast was observed when a sample of autistic adults was compared with a sample of nonautistic adults. We conclude that intelligence has been underestimated in autistics.

Courchesne, V., Meilleur, A.-A.S., Poulin-Lord, M.-P., Dawson, M., & Soulières, I. (2015), Autistic children at risk of being underestimated: school-based pilot study of a strength-informed assessment, *Molecular Autism*, 6:12 (open access here)

> Abstract: An important minority of school-aged autistic children, often characterized as 'nonverbal' or 'minimally verbal,' displays little or no spoken language. These children are at risk of being judged 'low-functioning' or 'untestable' via conventional cognitive testing practices. One neglected avenue for assessing autistic children so situated is to engage current knowledge of autistic cognitive strengths. Our aim was thus to pilot a strength-informed assessment of autistic children whose poor performance on conventional instruments suggests their cognitive potential is very limited. Thirty autistic children (6 to 12 years) with little or no spoken language, attending specialized schools for autistic children with the highest levels of impairment, were assessed using Wechsler Intelligence Scale for Children (WISC-IV), Raven's Colored Progressive Matrices board form (RCPM), Children's Embedded Figures Test (CEFT), and a visual search task. An age-matched control group of 27 typical children was also assessed. None of the autistic children could complete WISC-IV; only six completed any subtest. In contrast, 26 autistic children could complete RCPM, with 17 scoring between the 5th and 90th percentile. Twenty-seven autistic children completed the visual search task, while 26 completed CEFT, on which autistic children were faster than RCPM-matched typical children.Autistic performance on RCPM, CEFT, and visual search were correlated. These results indicate that 'minimally verbal' or 'nonverbal' school-aged autistic children may be at risk of being underestimated: they may be wrongly regarded as having little cognitive potential. Our findings support the

usefulness of strength-informed approaches to autism and have important implications for the assessment and education of autistic children.

Nader, A., Courchesne, V., Dawson, M., & Soulières, I. (2016), Does WISC-IV Underestimate the Intelligence of Autistic Children?. ***J Autism Dev Disord*** **46, 1582-1589** (paywall access here)

> Abstract: Wechsler Intelligence Scale for Children (WISC) is widely used to estimate autistic intelligence (Joseph in The neuropsychology of autism. Oxford University Press, Oxford, 2011; Goldstein et al. in Assessment of autism spectrum disorders. Guilford Press, New York, 2008; Mottron in J Autism Dev Disord 34(1):19–27, 2004). However, previous studies suggest that while WISC-III and Raven's Progressive Matrices (RPM) provide similar estimates of non-autistic intelligence, autistic children perform significantly better on RPM (Dawson et al. in Psychol Sci 18(8):657–662, doi:10.1111/j.1467-9280.2007.01954.x, 2007). The latest WISC version introduces substantial changes in subtests and index scores; thus, we asked whether WISC-IV still underestimates autistic intelligence. Twenty-five autistic and 22 typical children completed WISC-IV and RPM. Autistic children's RPM scores were significantly higher than their WISC-IV FSIQ, but there was no significant difference in typical children. Further, autistic children showed a distinctively uneven WISC-IV index profile, with a "peak" in the new Perceptual Reasoning Index. In spite of major changes, WISC-IV FSIQ continues to underestimate autistic intelligence.

Kasari, C., Brady, N., Lord, C., & Tager-Flusberg, H. (2013), Assessing the minimally verbal school-aged child with autism spectrum disorder, ***Autism Research: Official Journal of the International Society for Autism Research*****, 6(6), 479–493** (open access here)

> Key Quotation: "It is important not to place too much emphasis on the standard scores obtained in an evaluation. For many minimally verbal children with ASD it may not always be clear whether a specific test captures their abilities. For example, some children may participate more readily on the Leiter especially if they have had ABA type interventions in which matching is taught. The Leiter involves a series of cards to match or sequence, and some children may be more successful with this format than others. The Raven's Progressive Matrices, also a nonverbal test, involves somewhat more complex verbal instructions; thus, its utility may be more appropriate for older or higher cognitive level children. Despite widespread use of measures on non-verbal cognition, only a few studies have observed the validity of these measures with school-aged children with autism."

Tager-Flusberg, H., & Kasari, C. (2013), Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum, ***Autism Research: Official Journal of the International Society for Autism Research*****, 6(6): 468-478** (open access here)

> <u>Key Quotation:</u> “One significant barrier is the dearth of valid, reliable and appropriate means for direct assessments of this population. Instead, most studies that do report on some characteristics of their sample rely on parent report measures (questionnaires or interviews) rather than clinical testing. Standard methods for assessing even foundational cognitive or receptive language skills depend on a range of behaviors that may not part of the repertoire of the minimally verbal child. These include the ability to develop rapport with the examiner, the motivation to comply with task demands, capacity to understand the pragmatics of the testing situation, attention or interest in the testing materials, interference from challenging behaviors, anxiety or frustration, and basic responses such as pointing skills (Tager-Flusberg, 1999). For all these reasons it is often not possible to conduct direct assessments using currently available standardized tests (but see the companion paper on current options for assessing this population; Kasari, Brady, Lord and Tager-Flusberg).”

Wilkinson, K.M., & Rosenquist, C. (2006), Demonstration of a method for assessing semantic organization and category membership in individuals with autism spectrum disorders and receptive vocabulary limitations, *Augmentative and Alternative Communication*, 22:4, 242-257 (paywall access here)

> <u>Key Quotation:</u> “A recognized challenge in the field of augmentative and alternative communication (AAC) is the assessment of the individual skills and preferences of potential users of AAC. Particularly in cognitive assessment, many traditional methods are inappropriate because they require the participant to produce a verbal response and/or involve complex verbal instructions. For individuals with limited verbal forms of language, failure at such tasks is relatively uninstructive, either for revealing their functional intellectual status or for developing effective interventions.”

Bal, V.H., Katz, T., Bishop, S.L., & Krasileva, K. (2016), Understanding definitions of minimally verbal across instruments: Evidence for subgroups within minimally verbal children and adolescents with autism spectrum disorder, *Journal of Child Psychology and Psychiatry*, 57:12, 1424-1433 (paywall access here)

> <u>Key Quotations:</u>
> - “Minimally verbal (MV) children with autism spectrum disorder (ASD) are often assumed to be profoundly cognitively impaired and excluded from analyses due to challenges completing standardized testing protocols. A literature aimed at increasing understanding of this subgroup is emerging; however, the many methods used to define MV status make it difficult to compare studies.”
> - “This cautions against the assumption that minimally verbal is synonymous with cognitive impairment.”

Edelson, M.G. (2006), Are the majority of children with autism mentally retarded?: A systematic evaluation of the data, *Focus on Autism and Other Developmental Disabilities*, 21: 66-83 (paywall access here)

> Abstract: There are frequent claims in the literature that a majority of children with autism are mentally retarded (MR). The present study examined the evidence used as the basis for these claims, reviewing 215 articles published between 1937 and 2003. Results indicated 74% of the claims came from nonempirical sources, 53% of which never traced back to empirical data. Most empirical evidence for the claims was published 25 to 45 years ago and was often obtained utilizing developmental or adaptive scales rather than measures of intelligence. Furthermore, significantly higher prevalence rates of MR were reported when these measures were used. Overall, the findings indicate that more empirical evidence is needed before conclusions can be made about the percentages of children with autism who are mentally retarded.

Eagle, R.S. (2002), Accessing and assessing intelligence in individuals with lower-functioning autism, *Journal of Developmental Disabilities*, p. 45-53 (open access here)

> Key Quotations: "It is often taken for granted that the non-speaking and/or non-attentive individual with autism is non-cognitive, non-verbal and unaware, and that the severe behavioural difficulties that may render the individual 'untestable', denote lower intelligence. The low scores of these individuals on standard tests of intelligence appear to 'confirm' this supposition. In some cases, the suppositions may be true. In many cases, however, people who 'know' the autistic individual will suspect, or feel certain that there is much more awareness and thought than the tests have been able to access and reveal."

Other/General

Harrison, A.H., & Connolly, J.F. (2013), Finding a way in: A review and practical evaluation of fMRI and EEG for detection and assessment in disorders of consciousness, *Neuroscience and Biobehavioral Reviews*, 37:8, 1403-1419 (open access here)

> Abstract: Diagnoses and assessments of cognitive function in disorders of consciousness (DOC) are notoriously prone to error due to their reliance on behavioural measures. As a result, researchers have turned to functional neuroimaging and electrophysiological techniques with the goal of developing more effective methods of detecting awareness and assessing cognition in these patients. This article reviews functional magnetic resonance imaging (fMRI) and electroenchphalography (EEG)-based studies of cognition and consciousness in DOC, including assessment of basic sensory, perceptual, language, and emotional processing; studies for detection of conscious awareness; paradigms for the establishment of communication in the absence of behaviour; and functional

connectivity studies. The advantages and limitations of fMRI and EEG-based measures are examined as research and clinical tools in this population and an explanation offered for the rediscovery of the unique advantages of EEG in the study of DOC.

Major Point: Finds that assessment tools that rely on behavioral output do not tell us anything about the cognitive ability of individuals who cannot speak or move reliably

Borthwick, C., & Crossley, R. (1999), Language and retardation, *Psycholoquy*, 10:38, 1 (paywall access here)

Abstract: The diagnostic link between lack of speech (in the absence of deafness or obvious structural impairment) and mental retardation depends on the premise that behaviour is in general an accurate reflection of internal mental processes, and that nothing is inhibiting the overt production of communication and "masking" more sophisticated language. This premise is not always valid, and the methods for determining whether it is valid may not be the ones now practised in the field of mental retardation psychology. This article reviews several cases in which people with deafness, physical handicap, and learning disabilities were reclassified out of the category of mental retardation. The recent debate over “facilitated communication” suggests that the burden of proof may lie with those who hold that the actual expressive communication of people diagnosed as mentally retarded does adequately represent their internal language.

Major Point: Without access to AAC to enable a person to represent their thoughts to others, it is difficult if not impossible to accurately measure that person’s intelligence.

Kliewer, C., Biklen, D., & Petersen, A. (2015), At the End of Intellectual Disability, *Harvard Educational Review*, 85(1): 1-30 (open access here)

Key Quotations: “Goddard, an avowed eugenicist, had been struggling to develop a reliable social Darwinian scale for sorting individuals cast as mentally defective. In his revision of Binet’s test, Goddard (1911) believed he had formulated an apt tool to identify—and thus control—those deemed to be defective. His revision introduced the attribution of a numeric mental age to an individual. This construct suggested that one’s total intellectual performance could be expressed as the chronological age at which an average person was said to reach the same abilities. Following this adjustment to Binet’s measure, Lewis Terman (1916) developed an iteration now known as the Stanford-Binet Intelligence Scale. IQ tests, most often divided into subsections, were said to assess a subject’s capacity to reason using novel information, referred to as fluid intellect, and to effectively make use of existing knowledge to solve problems. Terman (1916), in authoritative terms, expounded on Goddard’s eugenics philosophy by suggesting, “[Through the IQ test] there will be discovered enormously significant racial differences in general intelligence, differences which cannot be wiped out by any scheme of mental culture" (p. 91).... Subsequently, the Stanford-Binet IQ was accepted by scholars and the general public alike as a predictive statistic that falls along a bell-shaped curve (Lewontin et al., 1984). Those who scored poorly or who were deemed to have less intelligence were thus perceived by psychologists and educators as possessing an objective and measurable disconnectedness from valued citizenship and full humanness (Smith, 1999)."