

Breaking the Communication Barrier: Why AAC Must Be Free and Open Source

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Executive Summary

A devastating crisis exists in Augmentative and Alternative Communication (AAC): individuals who cannot speak are systematically denied access to communication tools through a broken system of inflated pricing, insurance barriers, and proprietary lock-in. **Dedicated AAC devices cost \$10,000-\$20,000—representing a 600-800% markup over comparable iPad-based solutions that cost \$600-\$1,200**. Manufacturers strategically price devices at insurance reimbursement thresholds, creating a system where 84% of white families obtain AAC access while only 32% of racial/ethnic minority families do. The Autistic Self Advocacy Network calls this "a human rights crisis."

Commercial AAC solutions like Tobii Dynavox's TD I-Series (\$15,000-\$20,000) and PRC-Salttillo's Accent devices (\$10,000-\$20,000) dominate a market where insurance approval takes 2-6 months minimum, denial rates are high, and families without coverage face impossible choices. Meanwhile, modern technology enables AI-powered, open-source AAC applications running on consumer devices at near-zero cost. **Communication is a human right, not a product**. This paper documents the systematic failures of the current AAC market and makes the case that open-source, freely available AAC software represents both an ethical imperative and a practical solution to a healthcare system that routinely writes off nonspeaking individuals.

The Healthcare Insurance Crisis: A System Designed to Deny Communication

Strategic Pricing Tied to Insurance Reimbursement

The AAC device market operates on a fundamental premise: prices are set not by manufacturing costs or development expenses, but by insurance reimbursement limits. A 2024 market analysis revealed explicit evidence: **"Manufacturers like Tobii Dynavox and PRC-Salttillo now offer tiered pricing models aligned with insurance reimbursement thresholds. For instance, mid-tier devices are frequently priced at \$7,500-\$9,000—the maximum reimbursement limit under many European healthcare plans."**

Consider the absurdity: speech-language pathologists note that an iPad with Proloquo2Go costs approximately \$650 (\$500 iPad + \$150 app during sales), while comparable Tobii Dynavox devices run \$6,000-\$8,000. This **600-800% markup** exists primarily because manufacturers price to capture maximum insurance reimbursement, not because the technology justifies it. One SLP wrote: "The iPad 64GB runs approximately \$899 versus the Dynavox devices that run between \$6,000-\$8,000." The price difference funds not superior technology, but a business model built on insurance billing.

The evidence is damning. A 2023 ASHA report found that **38% of surveyed clinicians noted reimbursement-driven pricing leaves uninsured patients unable to access essential mid-range devices**. Suppliers exploit bundling schemes, packaging AAC devices with non-covered accessories like mounts or cases, inflating total costs by 25-40%. The parallel to pharmaceutical pricing fraud is unmistakable—the same False Claims Act provisions that recovered over \$2 billion from pharmaceutical companies for inflated Average Wholesale Prices apply to medical device pricing, yet AAC manufacturers operate with impunity.

Insurance Barriers: A Bureaucratic Gauntlet

Even families with insurance face a deliberately complex obstacle course. Medicare requires face-to-face examinations within 6 months, extensive documentation from speech-language pathologists, physician prescriptions, and proof that speech therapy "isn't working"—a catch-22 that forces families to demonstrate failure before accessing communication tools. The timeline? **Initial review takes 30-60 days minimum, with appeals adding 2-6 months per cycle. Total time from evaluation to device receipt often exceeds 6-12 months.**

Private insurance presents similar barriers. Documentation requirements include current speech/language evaluations (within 6-12 months), medical necessity justifications, AAC assessments from qualified SLPs, and proof of failed alternatives. Main issue: **insurance companies have the right to deny coverage, placing the financial burden entirely on families.** Multiple rounds of denials are common before approval. Even Medicare beneficiaries using AAC devices pay over \$1,200 annually in non-reimbursed ancillary costs.

Medicaid coverage, while mandated in every state, varies wildly in criteria and implementation. As "payer of last resort," families must exhaust all other funding first. The evidence shows the impact of this variability: **states with Medicaid AAC coverage mandates saw 62% higher device adoption rates** compared to non-mandate states. This single statistic proves that access barriers are artificial—purely administrative constructs that could be eliminated through policy.

The Human Cost: Racial Disparities and Systemic Exclusion

A groundbreaking 2024-2025 study by Children's Hospital Los Angeles revealed the starkest evidence of systemic inequality: **84% of white families had access to AAC devices for minimally verbal children, compared to only 32% of racial/ethnic minority families**. Even more devastating, 55% of families from racial/ethnic minorities had no prior knowledge that AAC devices exist, compared to just 12% of white families. Dr. Charlotte DiStefano, lead psychologist, stated simply: "These are striking numbers."

The financial burden compounds existing inequalities. The CDC reports that caring for an autistic child costs \$17,000+ more annually than a non-autistic child, with severe autism adding \$21,000+ in additional annual costs. Without insurance coverage, families face one-time device costs of \$3,000-\$15,000 plus ongoing expenses—expenses that are literally impossible for families already managing enormous out-of-pocket medical costs.

Globally, the access crisis is even worse. North America sees 40% adoption among speech-impaired individuals. In India, only 3% of children with complex communication needs use AAC (only 12% have health insurance covering assistive technology). Sub-Saharan Africa? Fewer than 5% of clinics even stock AAC devices.

Being Written Off by Society: The Consequences of Communication Deprivation

"A Human Rights Crisis"

The Autistic Self Advocacy Network (ASAN) doesn't mince words: **"Communication is a human right. People with speech-related disabilities, including nonspeaking autistic people, need immediate access to robust Augmentative and Alternative Communication (AAC.) As the largest self-advocacy organization representing the autistic community, including nonspeaking autistics, ASAN witnesses routine and widespread deprivation of this basic human rights."**

What does communication deprivation look like in practice? It begins with educational segregation. Nonspeaking autistic children are almost always placed in segregated classrooms away from nondisabled students, sometimes not even taught to read or write. The presumption of incompetence follows them throughout life: many nondisabled people assume that people with significant speech disabilities are incapable of making decisions, treating them like young children regardless of their age. **"It is not possible to truly assess for these conditions if the person does not have fluent access to robust communication,"** ASAN notes, highlighting the circular logic that denies assessment tools while using lack of demonstration as evidence of incapacity.

Real Stories of Exclusion

Jordyn Zimmerman, now Board Chair of CommunicationFIRST and a Presidential Committee appointee, had no access to effective communication until age 18. Teachers restrained and secluded her, assuming she was "too intellectually disabled to meaningfully communicate." Today, she advocates nationally but still faces discrimination: **"I am often denied access to my communication device when receiving medical treatment. When this happens, I can't communicate my symptoms, ask questions, or provide informed consent."**

Sharisa Kochmeister, an autistic advocate documented by ASAN, was placed under guardianship and denied access to her Lightwriter AAC device. Without it and without trusted friends or family, she was "effectively denied an opportunity to express her own wishes" and placed in a "host home" with location withheld from supporters.

The "Arlington Five" case exemplifies institutional barriers: five nonspeaking autistic students in Arlington, Virginia were denied communication supports by school administrators who refused to accommodate AAC users. One student was told he was "not welcome back" after his family requested communication accommodations.

The Cycle of Isolation and Trauma

Research documents a vicious cycle: negative societal attitudes breed social isolation, isolation limits opportunities for meaningful interactions, limited interactions perpetuate negative attitudes, and the cycle deepens. AAC abandonment—when individuals stop using devices even when still needed—occurs in one-third of client cases. Studies found that **88% of parent-carers, 80% of educators, and 100% of clinicians mentioned experiencing negative attitudes towards AAC use .**

Bob Williams, Co-Founder and Policy Director of CommunicationFIRST, used an alphabet board painted by a camp counselor at age 13. He used a Hall-Roe communication board through high school and college, even using it to lobby for passage of the Americans with Disabilities Act. He didn't get his first speech-generating device until age 33 in 1990. His

reflection: **"Oppression takes place when we are not heard and are not seen."**

College student Blasko, an AAC user, observes: "Without public awareness and understanding of AAC users, this results in us being **systemically ignored and excluded**." The consequences extend beyond loneliness to significant impacts on both physical and mental health, creating trauma from communication deprivation itself.

One parent of a nonspeaking autistic son described their daily reality: "When I get up in the morning, I say, 'Thank God he's not dead,' and 'Thank God I'm not dead.'" This is the human cost of a system that prices communication tools beyond reach.

Commercial AAC Solutions: Technology and Cost Analysis

The Major Players

Tobii Dynavox dominates the high-end market with devices featuring proprietary eye-tracking technology:

- **TD I-Series (I-13 and I-16)** : \$15,000-\$20,000, Windows-based, 13" or 16" screens, outdoor-capable eye-tracking
- **TD Pilot** : \$8,000-\$12,000, iPad 12.9" with integrated eye-tracking
- **Indi** : \$999 consumer-focused device (the lone affordable option)

Software includes TD Snap/Snap Core First, using the PCS symbol system (75,000+ symbols in 25+ languages) with Progressive Language features and core word vocabulary approaches.

PRC-Salttillo (Prentke Romich Company) has 50+ years in AAC, specializing in Unity language systems:

- **Accent 1400** : \$15,000-\$20,000, 14" screen, splash/dust-resistant
- **Accent 1000** : \$12,000-\$18,000, 10" screen
- **Accent 800** : \$10,000-\$15,000, 8" screen
- **Via Pro** : \$8,000-\$12,000, iOS-based

Their LAMP Words for Life app costs \$399.99 (one-time) for iOS, while TouchChat HD with WordPower costs \$299.99. Both use the Language Acquisition through Motor Planning (LAMP) methodology with consistent motor patterns for vocabulary access.

AssistiveWare's Proloquo2Go represents the mid-range option at \$249.99 (one-time purchase) for iOS/Mac, offering 100+ voices, 25,000+ symbols, and flexible vocabulary customization.

Budget alternatives like CoughDrop (\$9/month or \$295 lifetime) and Avaz (\$99.99/year) provide cross-platform solutions with cloud synchronization and team collaboration features.

Technology Stacks: Nothing Revolutionary

The technology underlying these commercial solutions is straightforward:

- **iOS apps** : Swift or Objective-C with UIKit/SwiftUI frameworks, Xcode development
- **Android apps** : Kotlin or Java with Android Studio
- **Windows devices** : C++ or C# on Windows 10 Pro
- **Cloud services** : Firebase, CloudKit, Google Cloud, AWS for backend
- **Voice synthesis** : Acapela, Acapela Neural, Apple system voices, Nuance voices
- **Symbol libraries** : PCS (owned by Tobii Dynavox) and Symbolstix

There is no proprietary magic here—these are standard development platforms using widely available frameworks. The eye-tracking in Tobii devices represents genuine specialized engineering, but the software layer uses conventional iOS or Windows development. The 600-800% price markup is not justified by technical sophistication.

The Cost Breakdown

Solution Type	Price Range	Platform	Insurance Coverage
High-tech SGD (eye-tracking)	\$15,000-\$20,000	Windows/iOS	Usually covered
Mid-tech SGD (touch-based)	\$8,000-\$12,000	Windows/iOS	Often covered
Commercial iOS apps	\$150-\$400	iOS	Rarely covered
Subscription apps	\$9-\$100/year	Multi-platform	Rarely covered
Consumer tablet + app	\$600-\$1,200	iOS/Android	Sometimes iPad covered

The pattern is clear: **devices priced in the insurance coverage range (\$8,000+) receive approval, while more affordable alternatives (\$600-\$1,200) face denials**. The system incentivizes higher prices, not better outcomes.

Open Source AAC: Freedom, Innovation, and User Control

The Movement: OpenAAC and Beyond

OpenAAC leads the charge "to get high-quality AAC into the hands of as many people as can use it," driven by the belief that "AAC users should have freedom to control their own destinies, that life opens and expands with effective communication." Their mission: **"remove the financial barriers that stand in the way of communication for too many."**

Major open-source projects include:

Cboard (<https://www.cboard.io/> (<https://www.cboard.io/>)): Free, open-source AAC web app funded by UNICEF, available in 40+ languages using the Mulberry Symbol Set (3,400+ symbols). Founded by Martin Bedouret, diagnosed with ALS in 2015, it works on any device with internet access and has been officially adopted by Philadelphia School District for pilots "in regions with little access to accessible assistive technology."

Open Board Format (.obf/.obz) : A standardized file format enabling users to import/export vocabularies across apps, directly addressing the vendor lock-in problem. Brian Whitmer explains: **"Right now if a communicator's device breaks unexpectedly or they find a better app for their needs, they pretty much have to start from scratch."** OBF changes this by making vocabulary data portable.

CoughDrop : Already discussed in commercial solutions but built with open-source principles, offering the most affordable subscription (\$9/month) with cross-platform cloud synchronization.

Modern AI-Powered Open Source AAC: The Technology Advantage

Contemporary open-source AAC development leverages technologies unavailable when current commercial solutions were designed:

AI and Machine Learning Integration:

- **Large Language Models (LLMs)** : Modern AI can provide predictive text, contextual suggestions, and natural language processing to accelerate communication. OpenAI's APIs, open-source models like Llama 2, or on-device processing with Core ML enable intelligent word prediction far beyond simple frequency-based autocomplete.
- **Computer Vision** : Object recognition can automatically suggest relevant vocabulary based on camera input, helping users learn new words in context.
- **Natural Language Understanding** : AI can interpret incomplete or grammatically imperfect utterances and suggest complete expressions, reducing the motor planning burden.
- **Voice cloning** : Modern neural voice synthesis can create personalized, natural-sounding voices from small audio samples, far superior to robotic text-to-speech.

Modern iOS/Android Development:

- **SwiftUI and Jetpack Compose** : Contemporary declarative UI frameworks enable rapid development of accessible, customizable interfaces.
- **On-device ML** : Apple's Core ML and Google's ML Kit enable sophisticated processing without requiring internet connectivity or cloud costs.
- **Accessibility APIs** : Modern platforms offer extensive built-in accessibility features (VoiceOver, Switch Control, Personal Voice) that open-source apps can leverage.

Cloud and Collaboration:

- **Firebase/Supabase** : Free or low-cost backend services enable cloud synchronization, vocabulary backup, and team collaboration features.
- **Open Symbol Libraries** : Projects like Mulberry Symbol Set (3,400+ symbols) and OpenMoji provide free alternatives to proprietary PCS/Symbolstix.

Importantly : A modern open-source AAC application built with Swift for iOS, leveraging AI for predictive text and contextual suggestions, using free symbol libraries and cloud services, can equal or exceed the functionality of \$10,000-\$20,000 commercial devices at near-zero cost to end users.

Why Open Source Is Ethically Imperative

Communication as a Human Right : CommunicationFIRST Board Chair Jordyn Zimmerman states unequivocally: **"Communication is a basic right."** The National Joint Committee's Communication Bill of Rights declares people have "the right to individualized, working augmentative and alternative communication (AAC) systems and other

assistive technology (AT) at all times." A human right cannot be ethically gated behind paywalls and proprietary restrictions.

Against Vendor Lock-In : When AAC users adopt an app, personalization takes many hours of customization. Proprietary systems trap users—if the device breaks, the company discontinues the product, or the user needs different features, years of work is lost. OpenAAC advocates note: "There are people who hunt for 10+-year-old devices on eBay so that they can keep using the communication tool that works best for them." Open standards and exportable data eliminate this dependency.

Community-Driven Development : The FreeSpeech success story exemplifies co-design benefits. A developer created an AAC app WITH his nonspeaking daughter Della as an active participant. Her input led to critical features like an optional sentence builder that made communication "10x more effective" for certain users. The problem, the developer noted, is that **"AAC software's inability to meet users where they're at, communication-wise"** stems from building without user involvement. Open source enables this participation.

Transparency and User Control : OpenAAC recognizes that "some users may be editing or deleting buttons as a method of communication and may feel they are being silenced or forcibly-controlled if they are locked out." Open-source code can be audited, modified, and adapted to specific needs. Users control their own communication tools rather than being controlled by them.

Innovation and Adaptation : Open standards enable "easy interchange of boards between Apps and so open up the ecosystem for collaboration and innovation." Multiple implementations can compete on quality, iterate faster, and serve diverse needs without artificial restrictions. The 40+ languages in Cboard demonstrate what's possible when barriers fall.

Cross-Disability Solidarity : As Jordyn Zimmerman notes: "Cross-disability, which is really important because whether someone is autistic or has ALS, our human rights and the discrimination that we face related to communication access is similar." Open source serves all disabilities without discrimination.

Real Success Stories

Cboard's Global Impact : Nearly 6 years of free service, adopted by school districts, available in 40+ languages, reaching under-resourced regions where commercial AAC is impossible.

FreeSpeech/Della : Co-designed with the developer's nonspeaking daughter, enabling her to link ideas "that she was never able to do before with other AAC apps." Featured in GitHub's Coding Accessibility series as an exemplar.

Open Board Format Adoption : Multiple apps (Cboard, CoughDrop, AsTeRICS Grid, PiCom) now support OBF, enabling vocabulary portability and reducing vendor lock-in risk for thousands of users.

The Case for Open Source: A Call to Action

The evidence is overwhelming:

1. **The current system is broken :** Prices inflated 600-800% above comparable technology, insurance processes taking 6-12+ months, denial rates that create 84% vs 32% racial disparities in access.

2. **The consequences are devastating** : Educational segregation, presumption of incompetence, social isolation, trauma from communication deprivation, systematic exclusion from healthcare, education, employment, and community life.
3. **The technology is available** : Modern AI, machine learning, iOS/Android development frameworks, cloud services, and open symbol libraries enable sophisticated AAC solutions at near-zero cost.
4. **The ethical framework is clear** : Communication is a human right. The Communication Bill of Rights, disability rights organizations, autistic self-advocates, and international human rights frameworks all affirm that denying access to communication tools violates fundamental human dignity.
5. **Open source works** : Cboard, FreeSpeech, Open Board Format, and other projects demonstrate that community-driven, freely available AAC solutions can equal or exceed proprietary alternatives.

The FreeSpeech developer said it best : "Communication shouldn't be restricted just to people who can talk. People who are nonverbal have the same right to communication, and they shouldn't have to pay for it."

For teachers, therapists, family members: advocate for open-source AAC solutions in IEPs and clinical recommendations. For healthcare advocates and policymakers: recognize that the current insurance-driven pricing model creates unconscionable barriers. For open-source developers: your skills can literally give voice to millions of people denied communication access.

In AAC user testimony to policymakers, one individual observed: **"In our society, it is the loudest voices that get the resources. Yet, when communication or speech is the disability, advocacy is difficult. There is a desperate need to increase our volume so that our voices are heard."**

Open-source AAC increases that volume. It transforms communication from a privilege of the wealthy and insured to a right accessible to all. The question is not whether we have the technology—we do. The question is whether we have the will to dismantle a system that profits from silence.

Bob Williams used a painted alphabet board to lobby for the Americans with Disabilities Act before getting his first SGD at age 33. His words resonate today: **"Oppression takes place when we are not heard and are not seen."**

Open-source AAC ensures we are heard. It ensures we are seen. And it ensures that communication—the foundation of human connection, autonomy, and dignity—is finally recognized as the universal right it has always been.

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