Yes, You Can Change Medicaid

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In 1965, Medicare and Medicaid were created as part of Lyndon Johnson’s Great Society programs. These two key governmental insurance types are separate programs although the Centers for Medicaid and Medicare (CMS), a division of the Department of Health, oversees both of them. We will focus today on Medicaid, which is the single most important source of cochlear implant funding for children. Medicaid is health care for persons of all ages whose income and resources are insufficient to pay for healthcare. It is jointly funded by federal and state governments but is managed by the states.

What is EPSDT and what is its role in Medicaid coverage rules?
The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, developmental and specialty services. The acronym stands for:

- **Early:** Assessing and identifying problems early
- **Periodic:** Checking children’s health at periodic, age-appropriate intervals
- **Screening:** Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- **Diagnostic:** Performing diagnostic tests to follow up when a risk is identified, and
- **Treatment:** Control, correct or reduce health problems found.

EPSDT rules set the guardrails for how children receive benefits under Medicaid, including cochlear implants. Essentially if treatment of a disease or condition helps a child to develop, it must be covered. Cochlear implantation is covered by Medicaid for children in all 50 states. When children age out of the system (somewhere between age 18 and 21 years, depending upon the state), states set their own coverage rules for adults. Reimbursement levels are also determined by each state. Hence individuals whose initial implant(s) were covered by Medicaid, may not have coverage when they move to the adult side of their state’s Medicaid program.

Thanks to EPSDT, all children whose families are covered by Medicaid and meet specific state candidacy criteria, are eligible for cochlear implantation equipment and services including speech and auditory therapy, equipment replacement, batteries and parts. An estimated 60% of states cover CI services for adults who meet income and candidacy guidelines. But hope is not lost as steps can be made to advocate that your state cover this medical intervention. In 2018, Maryland changed its rules allowing for CI coverage for adults due to pressure applied by Disability Rights MD with support from the ACI Alliance and other local institutions including the Johns Hopkins Cochlear Implant Program. We provided the staff with CI background including research findings on quality of life, impact on employment, and lower overall health care costs. This was done through the regulatory process vs legislation with the Maryland Medicaid office publishing new rules on which ACI Alliance commented and provided guidance. Since its implementation in Maryland, surgeries on adults and parts/equipment for those over 21 have been covered.

Another area that can be addressed is reimbursement, which is poor in many states. Executive Director Donna Sorkin has successfully argued for increased reimbursement for the surgery in states. This is a path to pursue if reimbursement levels are so low as to threaten continuation of your CI program at your hospital. We can help you to analyze the possibility of pursuing this approach in your state.

But how do you make changes in your own state? Before undertaking this project, consider the following questions:

- What is the current environment for Medicaid within my state government? Would an enhancement in the program be considered right now?
- Who might I partner with to help organize and advocate? Other hearing health organizations? General disability groups? Local parent and consumer organizations?
- How large is the population that may be served with any changes? Young adults who received a CI under the pediatric Medicaid program and have now aged out? What about

continued on page 12
an individual adult not covered by Medicare but eligible for Medicaid coverage?

After you have pondered those questions, we suggest the following steps forward:

1. **Get your talking points in order.**
Highlight the cost and possible savings such a change would have but also the impact on quality of life. Discuss the impact for people who turn 22 (or 19 or 20 in some states) and no longer have access to equipment or replacement parts and what that means long term.

2. **Contact key people at the State Medicaid office such as the Director, Deputy Director, or a manager of policy.**
Explain what our goal is and if this is something they are interested in discussing and addressing. If they are willing to consider it, they might be able to make the changes through the regulatory process without legislative input.

3. **If that route is a dead end, then the legislative route is your best bet.**
If you work for a large university or hospital system that has a government relations office, we strongly suggest discussing changes to Medicaid with them. Not only can they connect you with key politicians and staff, but there is a chance they ask you to not move forward for any number of reasons.

4. **Finding a sponsor to carry the bill (i.e., introduce and support it) is vital.**
We suggest contacting someone who sits on the appropriate committee in one of the Chambers or someone who has been amenable to Medicaid changes in the past. They can help draft the legislation to fit your ask and the current law. When/if the bill is heard before a Committee, be prepared to provide testimony in support and ask your partners to do the same. ACI Alliance can also help gather support through State Champs and CI CAN.

5. **Be patient.**
While states often pass legislation far faster than the federal government, it can still take a few years for a variety of reasons.

If you decide you wish to pursue a process such as this, ACI Alliance is here to support our members interested in changing Medicaid in their state. Our advocacy networks—both State Champions and CI CAN—are able to help increase the number of voices calling for change. The stories from consumers and families are essential in personalizing the discussion such as the young adult implanted as a child, still in school but no longer receiving batteries and parts or the late deafened adult on Medicaid who hopes to work again after being implanted. ACI Alliance staff can also provide research, data, and talking points to support the argument for change. If you are interested in trying to change Medicaid in your state, please contact Nichole Westin at nwesitin@acilliance.org.