



# Complex Child E-Magazine

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## Medicaid Waivers Must Be Transferable from State to State by Susan Agrawal

Many families of children with special needs rely upon Medicaid waivers to help them shoulder the cost of providing medical, therapy, nursing, respite, and other services for their children. These waivers, which are jointly funded by both state and federal dollars, vary widely in eligibility requirements, services, waiting lists, and programs. As a result, if a family chooses or is forced to move from one state to another, major problems may ensue. It simply is not right that a child's services and benefits should change dramatically because the family needs to relocate to a different state.

Let's just take a look at a few examples:

*Jessica is an eight-year-old diagnosed with moderately severe Cerebral Palsy who also has a feeding tube and is on oxygen at night. She was born in Pennsylvania to an upper middle class family and has received nursing care since birth, as well as secondary Medicaid coverage, through one of her state's Medicaid waiver programs. Her family recently was transferred to Illinois. In Illinois, she does not qualify for the Medicaid waiver for children who are medically fragile since Illinois restricts this waiver to children with significant medical technology, such as a tracheotomy or ventilator. She does qualify for another waiver for children with developmental disabilities, but this waiver has a waiting list and does not provide nursing care.*

This case illustrates the great variability in medical eligibility between states. In Pennsylvania, a state known for providing extensive services for a wide variety of needs, Jessica received comprehensive services, including nursing and secondary Medicaid that covered costs not picked up by her private insurance.

A simple move across state lines, mandated by her father's employer, means that the family has to completely start over with the long process of applying for Medicaid waivers and other services, which, of course, cannot even be started until residency in the new state is established.

In Illinois, the waiver equivalent to Jessica's previous waiver is restricted to children with an extremely high level of medical technology and she does not qualify. She has instead been placed on the waiting list for a newer waiver intended for children with developmental disabilities. This waiver, which favors children with autism and behavioral issues, does not provide the same level of care or services and restricts the

total dollar amount of services each child may use per month. If a spot does open up on the waiver, Jessica is likely to only receive respite care by a non-medical provider. She will no longer receive nursing care.

Currently Jessica is receiving no services as her family waits for her name to come up on the waiting list. Their financial expenses, including copays, deductibles, prescription medication copays, and costs for therapy and equipment, have risen dramatically to about \$20,000 per year since Jessica cannot receive secondary Medicaid while on the waiting list. The family is struggling financially.

Let's look at another example:

*Jacob is a six-year-old diagnosed with severe Autism and several medical problems. He was born in Maryland to a middle class family and has been a part of their Autism Medicaid Waiver for the past three years, after a short wait on the waiting list. Through this waiver, he receives full Medicaid, therapy services, respite care, and wrap-around services after school. His family was recently transferred to Indiana. In Indiana, he does not qualify for the Autism waiver because their waiver looks at the financial resources of the entire family instead of just the child. As a result, he no longer receives any additional services beyond those provided by his school. He no longer receives respite, private speech therapy, or wrap-around services.*

Again, a child who received extensive services in one state is no longer able to receive services in another state. In this case, the financial eligibility requirements vary dramatically between the two states, and Indiana's Autism Waiver is restricted to families who earn less than 300% of the poverty line. Jacob's previous waiver only counted his income and assets, but Indiana's waiver counts the income and assets of the entire family. He has lost his full eligibility for the most appropriate waiver, and he does not qualify for any of Indiana's other waivers, which are few in number.

This loss of services has had a great impact on Jacob's family. Because he no longer receives wrap-around services after school, his behavior has become very problematic. His parents are exhausted and receive no respite care. Their private insurance does not cover speech therapy or daily behavioral services, and Jacob is no longer making progress with communication, making his behavior even worse. The family is unable to pay out-of-pocket for these expensive services.

Jacob's mother is considering quitting her part-time job because the family would then become financially eligible for waiver services. While she is the main breadwinner of the family, her husband's employer provides the family's health insurance and he is thus unable to leave his job. The family would suffer financially if Jacob's mother quit her job, most likely forcing them to sell their home, but at least Jacob would be able to receive the services he so desperately needs.

These are just some of the difficult decisions and consequences that can come about with a simple move from state to state. Children may lose benefits or eligibility completely,

children must start again at the bottom of waiting lists, and families must make impossible choices to try to make ends meet to get needed services for their children.

It is my belief that Medicaid waivers need to be made more portable from state to state, because it is simply not acceptable for Jacob and Jessica to have all of their needs met in one state and none met in another state. If a child requires a certain level of care and services, that child should receive those services no matter what state the child lives in.

Here are some proposals:

- All states must end waiting lists. If a child qualifies for a program, the child should be able to receive services through the program immediately. If this is something you support, see the website for the National Organization to End the Waitlists, <http://www.noewait.net/>
- While it is understandable that different states need different programs to deal with varying populations, all states must have at least basic programs in several core areas, including a program for children who are medically fragile and a program for children with developmental disabilities and autism.
- Income guidelines for these programs should be standardized, with all programs only looking at the child's income/assets.
- Medical or diagnostic guidelines need to be standardized so a child who is considered medically fragile in one state will be considered medically fragile in all states. In general, states with fewer residents or fewer children with disabilities have much looser requirements than populous states with many affected children. The services should be based on health status alone, and not how many individuals a given state can afford to cover.
- The federal government must shoulder a greater burden financially for these services, especially for populous states.
- States often restrict enrollment to these programs by intentionally not advertising or making explicit the details of their programs in simple language. All states should provide detailed information on their programs in easily accessible formats and clear language. A nationwide database of this information should be available on the internet for families to consult.

Will this cost more money? Most likely it will, especially if wait lists are eliminated. But it is our responsibility as citizens to provide for our children, and especially for the most vulnerable children with the greatest needs.

Moreover, these programs have been shown to be cost effective, in both the short term and the long term, depending on the situation. For example, a child with medical needs can be cared for at home for about two-thirds the cost of placing the same child in a

nursing facility and dramatically less than in a hospital, saving millions in the short term. Over the long term, early behavioral interventions and developmental training can help a child reach his full potential, allowing him to become an independent and employed adult in many cases.

It is time to end the waiting lists and provide comprehensive services to all children with medical needs and disabilities, regardless of their state of residence.