

# The Star-Ledger



PHOTOS BY JOHN O'BOYLE/THE STAR-LEDGER

Cassandra Alexandre, left, and Nakeishia Knox, both of Newark, at a meeting held by a support group for parents of special-needs children in Newark.

## Someone who's been there

Moms of special-needs children find help from a sympathetic source - other moms

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By **Carmen Juri**  
STAR-LEDGER STAFF

Cassandra Alexandre of Newark really needed a good cry.

For two years, she had bottled up the emotions that came with being the mother of an autistic child.

Though she was devastated when her 3-year-old son was diagnosed with autism, what followed was almost worse — she felt abandoned by family members and her church.

"Grandparents are not coming around anymore," said Alexandre, sobbing uncontrollably.

Then, as if addressing her family, she said, "It's not his fault. What hurts so much is, it's his birthday, and why aren't you calling him on his birthday?"



Donna Oakes of Newark, a Mom2Mom participant, with her son Dominick, 11.



Alexandre found an outlet for her tears and frustrations in a group of moms — moms who knew what she was talking about because they'd been there, too.

Alexandre and her audience of sympathetic ears — who meet each month at John F. Kennedy School in Newark, a middle-secondary special education school — are part of the Mom2Mom peer support initiative, coordinated by UMDNJ's University Behavioral HealthCare division in Piscataway.

The program, which began in Piscataway in 2010 and came to Newark this past fall, offers support groups and a 24-hour helpline, all staffed by other mothers of special-needs kids who have been trained to counsel moms in crisis.

### 'LIKE OTHER KIDS HAVE'

At the meeting, Donna Oakes, mother to an 11-year-old boy, told Alexandre she felt her pain.

"They won't come to Dominick's birthday party. People don't realize I want him to have things like other kids have," she said. "Family don't invite me over anymore."

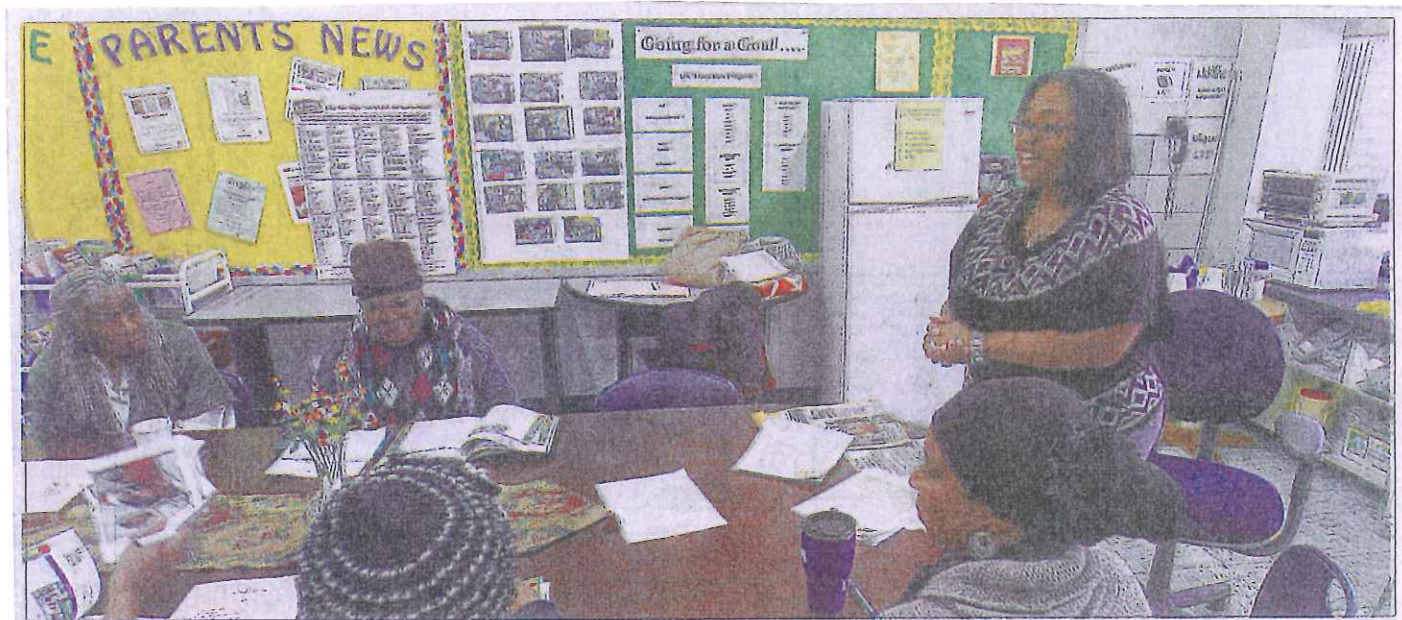
Having another mother in the same situation to advise and sympathize is the purpose of Mom2Mom, said Cherie Castellano, a crisis-intervention professional and program manager at Behavioral HealthCare. Castellano trains the peer counselors for the Mom2Mom program.

This group is the third peer support group launched by Castellano — she also started Cop2Cop for police officers more than a decade ago, and Vet2Vet for military veterans in 2005.

A \$91,000 grant from the Healthcare Foundation of New Jersey, a nonprofit group devoted to improving health care options in the Newark area, paid for the program in its first year. In 2011, Mom2Mom received another \$143,000 from the foundation.

"There really isn't anything that helps the mothers deal with this really intense, involving life-disrupting situation," said Marsha Atkind, the foundation's executive director.

Mom2Mom is focused on helping mothers cope — because other resources for families with special-needs kids largely focus on helping the children, but don't address the needs of their parents, she said. These moms may have jobs and other children to care for, she pointed out. And they may not have a spouse or partner.



JOHN O'BOYLE/THE STAR-LEDGER

**Nakeisha Knox of Newark speaks at a Mom2Mom meeting held at the John F. Kennedy School in Newark.**

"When you lay on top of that raising a child with special needs, and fighting for that child to have the best services and care, we realized (there) must be a tremendous need for support for these mothers," she said.

Callers to the help line are matched with a mother whose child has the same disability. If a mom is depressed, the peer counselor finds her professional help. If a mom is distressed because her child relies on equipment that runs on electricity, and the electric service has been cut off, the counselor can handle that, too.

"If it's a crisis, we handle it. The majority of the calls, they say, 'I can't believe you exist' or 'You're the answer to a prayer,'" Castellano said.

Peer counselor Nakeisha Knox, mom to a 15-year-old autistic son, said support groups have turned her off in the past because they felt like pity parties.

"Sometimes you find yourself coming out more depressed than (you were) coming in. They are so accepting of 'My child will never be nothing,' or 'Oh, he strived today because he tied his shoelaces and he's 25.' Are you serious? It's so disheartening. I'm not remotely going to put myself in that."

Still, at a friend's urging, she went to a Mom2Mom meeting. Castellano won her over.

"She was really speaking my language. It's like she got it," said Knox. "It was more like, 'Yeah, we're going through this, but there's a mom right here who has a 40-year-old child who works at a VA hospital.' There was hope."

The topic of one day's group session was the importance of faith in raising a child with special needs. Mary Beth Walsh of Maplewood, who holds a doctorate in theology and ethics — and is the mother of a 13-year-old autistic son — asked the group about their experiences at churches and other houses of worship.

Douglas Oakes, Donna's husband and the only father in the group, said one church called a meeting to complain that Dominick was too noisy.

Three years ago, Safiyyah Muhammad's then-10-year-old son was running around at a mosque, and someone asked, "Whose bad child was that?" Muhammad, an East Orange resident, recalled.

"I was devastated," she said

"If we have to accept people for their race and nationalities, how can you not accept people no matter what their disability?" asked Muhammad, a peer counselor.

Then Alexandre chimed in. A Catholic, she has been trying to schedule a baptism ceremony for her son, but the pastor will not return her calls. Walsh told Alexandre that pastor's refusal shows how hard moms have to work to advocate for their children.

Muhammad looked Alexandre straight in the eye and said, "It gets easier, or your skin just gets really tough.

"Or both."

*Carmen Juri:*

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## More info

Parents of special-needs children who need help can reach Mom2Mom via:

- A toll-free telephone helpline at (877) 914-6662
- Through live chat at [mom2mom.us.com](http://mom2mom.us.com)
- E-mail at [mom2mom@umdnj.edu](mailto:mom2mom@umdnj.edu)