Effort focusing on community's biggest needs

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Salvatore Amenta is a 67-year old Stouffville resident and father to a 30-year-old son with a mild intellectual disability.

Newmarket's Susan Popper has two children, a son, 28, and daughter, 25, with autism and degrees of developmental delay.

Both parents are principal caregivers to their adult children.

They, like a myriad of others, are increasingly worried given their ages and the state of respite and social services in York Region.

Conversely, they are buoyed by the recent announcement of a ground-breaking, threeyear, \$30-million United Way of York Region fundraising campaign. The agency is attempting to focus on each community's biggest needs and provide those services closer to home.

Still, time is ticking.

United Way's strategy is an "intriguing plan" and welcome news for people in the community living movement who have seen aging or ailing parents leaving their special needs adult children at the doorsteps of service agencies because they can no longer care for them, Mr. Amenta said.

With aging baby boomers, the number of families desperately needing help with their intellectually disabled children is growing at an alarming rate, he said. "There are serious gaps. There are terrible stories about parents too old or dying and their kids need 24-houra-day care.

'I hate to use the term abandoned in reference to local agencies, but many families are in dire straights.'

insight into the issues surrounding commu-increase funding for respite services. nity living. She is a volunteer co-chairperson and a group leader at Family Support Network. The non-profit agency rallies families York Region offering services. who network, provide mutual support and disabilities.

housed.

cial agencies.

However, about 12,000 adults in Ontario live at home with their family as caregivers, Ms Popper said. Many of whom are in 40s and 50s and still looked after by their senior parents in their 70s and 80s.

More than 15,000 Ontarians with developmental delays are on a wait list for community participation funding that can get them out of the house with support, she said, adding the queue spills over into York Region.

"The people waiting range from high need to high function," she said. "Nonetheless, families have to help them."

One of the most exasperating issues facing Ms Popper, Mr. Amenta and other caregivers is a void in comprehensive services once a challenged child is 21. Up to that chronological milestone, the province funds respite services and elementary and secondary schools offer special education and integration programs.

"Once the children transition out of school." there's not much support," she said.

Day programs exist, but they cost, she said. Her son, categorized as high need, receives Community and Social Services Ministry funding through the passport initiative to buy supports and services. Participants are usually only funded for 36 months. Her daughter is higher function and is looking for part-time

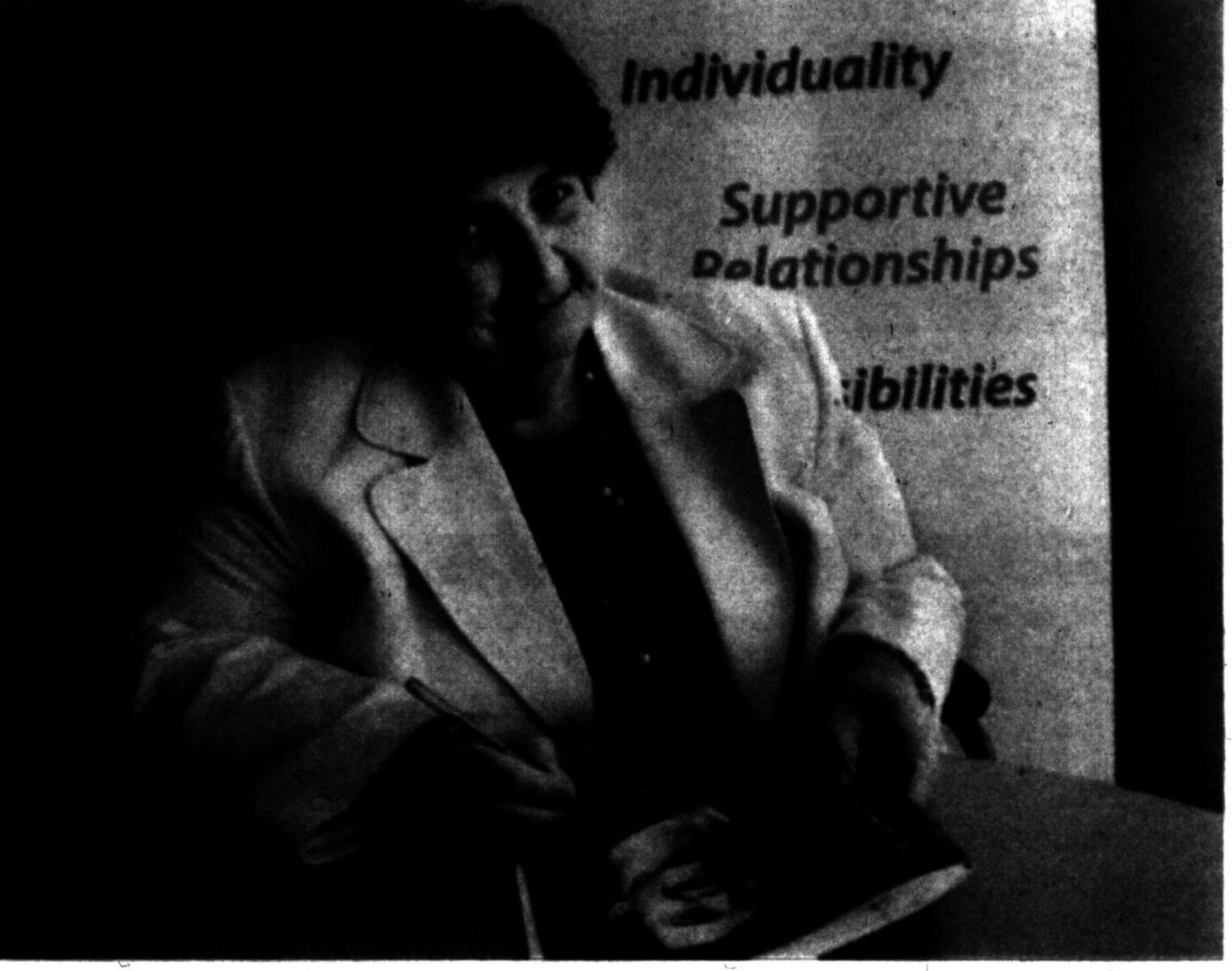
Ms Popper estimated there are up to 4,000 York residents with some form of developmental disability.

Mr. Amenta advocates for support and awareness. While he's grateful his son drives information, visit dnad.com and has a maintenance job at York's Safety Village, others, he said, are in a crisis situation. Demand for services outstrips supply and lies get respite services. people are falling through the cracks. Caregivers are stressed and stretched to the limit.

There's very little emotional, social or moral support for parents and caregivers, and respite services for people with intel-Ms Popper, has first-hand and historic he lamented. He would like to have Ontario

> There are about 12 provincially funded agencies and four private organizations in

Developmental Services Ontario is a proadvocate for children with developmental vincial agency that registers people with a disability and, through a detailed assessment Fifty years ago, children and adults with and score system, makes support fair and intellectual challenges were institutional- equitable. According to their May 2013 York ized, she said. Now, after concerted parental Region statistics, 2,040 residents are supportand political will, people are no longer ware- ed in group homes, apartments or with associate (foster-type) families. There are 1,311 People with disabilities live in the com- people in regional day programs where they munity. Some live in group homes, attend day receive care, participate in activities and learn programs and are looked after by 400 provin- employment and literacy skills. Some 90 fami-



STAFF PHOTO/SUSIE KOCKERSCHEIDT

Colleen Zakoor is executive director of Community Living Newmarket Aurora District.

► For Community Living Newmarket Aurora District

Community Living Newmarket Aurora District, founded in 1954, is a non-profit agency offering a range of residential, day lectual and physical challenges. The agency also offers associate family and employment supports. There are 243 adults and children under care in its residential and day programs.

Executive director Colleen Zakoor, a seasoned social service administrator, is candid about the state of community living.

"Oh yes," she answered in response to whether there are waiting lists. "We know there aren't enough programs for people to access. Is it all equitable? Not at all.

"The Ministry of Community and Social Services is grossly underfunding Community Living supports by 25 per cent in relation to Ministry funding for mental health and addiction."

The system needs to be on equal footing, she said. There are partial solutions beyond dollars and cents where families can band together and support each other. She has witnessed the communal spirit.

It's amazing, Ms Zakoor said. But there's also a breaking point.

Support and respite services feel fleeting for families and put them on edge, she said. Planning becomes difficult. Families with a challenged child 18 and older should consult Developmental Services Ontario, she advised.

Last month the Ministry of Community and Social Services announced a \$42.5-million investment, designed to help families and adults at high risk, reduce wait list pressures and better support those with complex needs.

"Although this support is helping many, it is still short of resolving the crisis situation for thousands more, Ms Popper said. "I volunteer and stay at home. It's a full-time job, believe me, and it's without pay."

