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VOR Weekly E-Mail Update
May 16, 2008

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FOCUS ON ARIZONA TRAINING CENTER AT COOLIDGE

1. Home invasion: The Arizona Training Program at Coolidge is the only home some developmentally disabled people have known

Coming Up: May 23: Focus on Aging Crisis (Texas, Nationa): "When Crisis Hits the Disabled - Limited Options for Support and Housing Exist for Aging Caregivers and Their Children"

1. Home invasion: The Arizona Training Program at Coolidge is the only home some developmentally disabled people have known

Summary:

This article provides an excellent history of deinstitutionalization leading up to the present day challenges for residents of the Arizona Training Program at Coolidge (ATPC), and their families. There is legislative and advocacy pressure to close the center, with families of residents, important legislators, and others. Among those supporting is ATPC is the former Director of the Arizona DD Council who helped close another AZ facility, but has now switched his position in support of ATPC because, "all the promises [about supports and community integration] made have not happened."

Megan Irwin, the reporter for this story, does a terrific job of laying out all the tired arguments in support of deinstitutionalization, from the stigma that continues to plague the very word "institution" to the alleged cost of running ATPC, while also showing the faults of these arguments. She points out that the strongest anti-ATPC advocate is a large private ICF/MR provider (Hacienda) who doesn't seem concerned that many anti-institution advocates and possibly some Arizona legislators, could ultimately address the similarity between ATPC and Hacienda - both are ICFs/MR and the fact that one is public and one is private doesn't make one any less a large ICFs/MR.

Ms. Irwin also took the time to visit ATPC, something many anti-institution advocates haven't done, and offers her observations:

"More than 100 of the people who live here are diagnosed with severe or profound disabilities, and therapy like this is how the staff keeps them active. No one spends all day in any one room. They all go to work, their retirement program, or therapy every weekday.

A tour of several of the living cottages reveals clean quarters, where most clients have their bedrooms decorated however they want (Spider-Man is popular here). Each room feels individualized with photos, some over 50 years old, of family members, and personal belongings such as china dolls (in a glass case) purchased for the residents. The facility just bought a \$10,000, high-tech bathtub to help caretakers bathe their fragile clients. One cottage is outfitted for the sight-impaired. Three-wheeled bikes are parked outside others.

In light of how familial ATPC feels, it's easier to understand why parents, guardians - and some others - are so insistent it stay open. [Note: A key contributor to this story was Deb Henretta, whose brother is a resident at ATPC and credits his survival for the care they have provided Vincent since his teens. Deb is a VOR member and is attending the VOR Annual Meeting and Washington Initiative to represent Arizona this June. Deb is also advocating for the development of a Community Resource Center at ATPC, which reporter Megan Irwin covers in some detail in this article].

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By Megan Irwin

May 01, 2008

Phoenix News Times

She was committing her boys to an institution called the Arizona Children's Colony. That's what you did in 1952 with children like the Arrington twins, born with cerebral palsy and severe mental retardation, destined to live life in a semi-vegetative state (though they would surpass their life expectancy many times over).

The day they were born, Arrington's doctor told her to take them to the state mental hospital at 24th and Van Buren streets in Phoenix. Instead, she brought them home, expecting to watch them die. Everyone told her to give up. When the twins both contracted staph infections around their second birthdays, a doctor agonized over whether to give them penicillin to save their lives. Arrington worked day and night to keep the babies alive, and she did it by herself.

In 1949, when Faye Arrington's sons were born, the implications of raising a disabled child were much different than they are today. There was no state Division of Developmental Disabilities to provide funding for therapy. There were no parental support groups. There was no nonprofit Arc or federal Americans with Disabilities Act.

"It took me 24 hours to feed them, and then I'd start all over again," says Arrington, now 75 and living off the little she saved working as a meat wrapper for more than 40 years. "I had no family supports, no nothing. And we were looked at as a bad family for having something like that."

She already had one daughter. She was pregnant with another who would also be born disabled. (Her husband divorced her and remarried after the birth of their fourth child.) She simply could no longer support young Darrell and Dorrell.

So on March 19, 1952, Arrington drove her boys from Mesa to the brand-new Arizona Children's Colony, six miles outside of Coolidge, a

town southwest of Phoenix near Casa Grande. They were the facility's first residents.

Darrell and Dorrell Arrington are still there today, curving toward each other in a perfect mirror image. They can't stand to be apart. Their mother says their wheelchairs have to be parked next to each other in church so Darrell can reach out for his younger (by five minutes) brother's arm. Once he grabs onto it, he falls asleep.

A couple of years ago, Faye Arrington brought her children home to Mesa for the first time in more than 50 years. She sent out invitations with photos of Darrell, Dorrell, and their younger sister Darla Kay. More than 70 family members showed up to meet them. Some didn't even know they were alive - or, for that matter, had ever been born - until that day. Staff from Coolidge drove the Arrington siblings to Mesa and sent a nurse along to take care of them.

At the end of the day, they returned to the center. After all, that is their home.

The Arringtons and the other 129 people who live at the facility now known as the Arizona Training Program at Coolidge (ATPC) spend their days in relative peacefulness, but the world around them has changed. Today, no one would dream of telling a mother to commit her handicapped child to an insane asylum, or any other kind of institution, for that matter. Starting in the '70s, the civil rights movement expanded to include people with disabilities and the truth about deplorable living situations in institutions began to come out. Nationwide, many facilities like ATPC have closed, as efforts are made to include developmentally disabled people in the community.

There's a huge stigma around the word institution - conjuring up images of shock treatments and One Flew Over the Cuckoo's Nest-style lobotomies. It's a picture that lingers in the minds of many disability advocates, who remember when ATPC was home to more than 1,000 people, with beds lined up in large barrack-style rooms and staff ill-equipped to take care of needy residents.

The picture is much different now. At the facility in Coolidge, things are tranquil. The Arrington twins, and others, are living out their "retirement" in a place where they are safe and well cared-for, according to their family members, staff at the facility and a bird's-eye view (a three-hour tour, earlier this year). In this case, the institution is anything but - it's their home, and it's the only one most of its residents have ever known.

But at the Arizona Legislature, the stigma lingers. Efforts are being made to shut the facility and move the residents into community group homes, or another intermediate-care facility. As it turns out, the man behind the current effort to close Coolidge is a direct competitor. He runs an Intermediate Care Facility for the Mentally Retarded in Phoenix, where it costs at least \$112,993 per resident per year, only marginally less expensive than Coolidge when it comes to the facilities' needier residents.

Such efforts are nothing new. At a local level, the movement to shut Coolidge began in 1979, with a legislative footnote that forbade new clients. Nationally, a larger movement to close institutions began in the '70s, when the President's Committee on Mental Retardation vowed to reduce the number of institutionalized people by a third. The Reagan years brought budget cuts and the closing of even more institutions, and an important U.S. Supreme Court case ruled against forced institutionalization in 1999.

And it was a good ruling. The institutions of the past were bad, and Coolidge's facility was no exception. But today, everything has changed except its reputation, which is the crux of the advocacy community's argument to shut it down.

Elliot Gory, a psychologist who has worked part time with clients at ATPC for 30 years, says trying to reconcile the current attitude toward institutions with the level of care ATPC clients receive is quite a dilemma.

"The clients at ATPC have lived their lives there. That's all they know," he says. "So here's the challenge: In America, the ethic is integration, and I certainly support that. But for these clients, that's all they've known."

The argument inside the Legislature, however, is clearly more about money. A bill to shut ATPC was introduced this year in the House Appropriations Committee and not, interestingly, in Human Services, the committee that generally deals with DDD legislation.

The bill was introduced by Republican Majority Whip John McComish, who says the facility must close because it's too expensive and because the clients can be better served elsewhere.

McComish did not respond to a request for an interview for this story, but he did explain his position at a legislative hearing on the bill held March 5.

"I found that the institutionalization, if that's the correct word, of the developmentally disabled community is not the accepted model today. Community-based care is the best care for people with developmental disabilities issues. The secondary point is that the Coolidge facility is more costly. Thirdly, it really takes very poor advantage of a very valuable state resource [the land it sits on]," he told the committee. At the hearing, he mentioned he had toured the Coolidge facility, as well as another large, privately run facility in Phoenix.

The bill was tabled at a hearing on March 12, but there's a rumor it could re-emerge in the Senate toward the end of the legislative session.

McComish used the word "institution" several times throughout his statement. It's a word disability advocates have a hard time overcoming.

But in the case of Coolidge, it's a misnomer. These days it's more a nursing home than anything else.

State Representative Pete Rios has fought the facility's closure throughout his entire 24 years in the Arizona Legislature. Rios is a well-known Democrat and former Senate president who represents the district in which ATPC - Coolidge's largest employer - is located. He's not running for re-election, and though he's always defended ATPC, he's now even freer with his opinions.

"I'm totally against the closure of that training center. First of all, because they're getting good care. These people that want to close it say the state should not be running an institution, a very bad image to conjure up," he says. "The training center in Coolidge [consists of] cottages. They're spread out, there's a lot of acreage. They have qualified staff, they have doctors, they have dentists and specialists. Not only should we not be closing the training center, we should be making these services available to others because it's a great resource."

But it's an expensive resource.

The center sits on 87 acres of the 320 acres of land owned by ATPC,

land designated by state law for use by the developmentally disabled. Those in favor of closing the facility wonder whether it is the best use for so many acres of land, and say it could be sold, with the profit going into the state's DD Client Services Trust Fund.

(However, on April 18, Governor Janet Napolitano approved budget cuts that hacked \$1.6 million from this account as well as \$1.8 million from a fund for early autism intervention - leaving many wondering if money from a land sale would actually end up filtering back to developmentally disabled people.)

McComish is right; it does cost money to run. It costs \$138,470 a year per person on average, and as the population dwindles, the facility becomes more expensive to operate. The cost of living at ATPC includes extras like dental care and specialized wheelchairs. By contrast, the annual cost per person in a group home is \$38,938 a year.

Keep in mind, by statute, Arizona group homes can hold no more than six people and do not include some of the benefits, like preventive dental care, that ATPC residents enjoy. They're also continuously understaffed, with a high turnover rate. Also, housing and attendant care for the Arrington twins and others like them would raise the figure a lot.

Coolidge residents live in cottages or larger dorm-like buildings, depending on their medical needs. And some of them are extremely medically needy in ways that go beyond the scope of their disability. Many are fed through G-tubes and in a semi-vegetative state. Some have lost their ability to speak; others never learned how.

The average age here is well over 50 - the average mental age is much younger. More than 100 of the people living here fall at the most severe end of the cognitive disability spectrum - and are dealing with the medical complications that come with age (blindness, Alzheimer's, and cancer, to name just a few) as well.

Still, everyone at ATPC has an individual program designed to keep residents as active as possible. Many spend their days at work (some go off-campus, others work piecemeal in a program designed for them to earn money) or at retirement programs specially designed for their needs. After work, they receive therapy. At meal times, they are served food prepared for them by a master chef from New York City. They have wheelchairs specially adapted on-site for any individual who needs one. The services are hard to get and expensive for people living in community settings.

Many of ATPC's employees have been there 30-plus years, and the clients have known each other their entire lives. They have friendships that are easy to observe, even on a casual tour of the grounds.

On a tour that lasted more than three hours, it was clear that nothing about the place feels dark, scary, or institutional.

Though 70 percent of the Coolidge residents have family members actively involved in decisions about their care, moving back into the family home would put an incredible burden on parents who are in the process of figuring out their own end-of-life needs.

Blinda Mills - the older sister of the Arrington twins and Darla Kay - says she's sure her mother would be dead if not for ATPC's help.

"I doubt she would be alive because of the strain," she says.

Mills knows what the facility's closure could mean for her family: She'd have to quit her job as a special education teacher and move back in with her mother to help out. The state would have to pay for round-the-clock nursing care and renovate the house to accommodate the three disabled Arringtons, all of whom are in wheelchairs, require

several hours of physical therapy each day, and are fed through G-tubes surgically placed in their stomachs. They also require almost constant stretching and physical therapy because of the crippling effect of cerebral palsy on their bodies.

Aside from the stress to her and her elderly mother, Blinda worries about what would happen to her siblings and other residents at ATPC. (They would bring their family members home, Blinda says. They don't trust other options.)

"It would be like a divorce or a death in the family for them," she says. "When you have been somewhere 50 years, that is your home. They know the grounds. They know the people. It makes me so mad. They're not cattle that you move from one pasture to the next."

At the time Fay Arrington's children were born, in the '40s and '50s, a disabled child was someone to be hidden from the community. Institutions were a big industry - in 1940, there were 100,000 people in state-run institutions around the country. By 1960, that number had doubled. Families with disabled children had to foot the bill for the children's care. Arrington had to pay for her children to stay at Coolidge until they were 19. There was no AHCCCS or state budget for long-term care. Willard Abraham, an education professor at ASU in the 1950s who focused on teaching both gifted and disabled children, wrote in his book *Barbara: A Prologue* about having a baby with Down syndrome. The book was written as a love letter and explanation to his late daughter, whom he institutionalized shortly after her birth, and dedicated to the "thousands of ill-finished children of generations to come." Abraham, who, ironically, worked with children at the Arizona Children's Colony (he even may have known the Arrington twins), agonized over his decision to institutionalize his daughter.

The book brings the mindset of the time sharply into focus: The family views this child as an utter tragedy. The mother cannot cope with the thought of a mentally retarded daughter. Abraham, an expert and well-educated man, never once calls his daughter's condition Down syndrome in the book - it's "mongoloidism" to him and his contemporaries.

Doctors offer Abraham advice that's shocking to the modern ear, but was considered normal at the time. A friend, then the director of the Arizona Children's Colony, tells him, "I always feel bad when parents are separated from their babies. Mongoloid children are so lovable and easy to get along with . . . [but] the time comes when institutions are better places for them to be."

Abraham and his wife did send their infant daughter to Valley of the Sun, a Phoenix facility, where she died of heart failure four months later. Heart problems are common for children with Down syndrome, and if Barbara had been born today, there's a good chance doctors might have been able to detect a defect and save her. Not so in the early 1950s. Even families who were financially able to take care of their disabled children were encouraged to send them away. The late playwright Arthur Miller had a son, Daniel, who has Down syndrome and was institutionalized in upstate New York for years. Miller apparently never mentioned or wrote about his son, according to an article published last year in *Vanity Fair*. It was as if he never existed. (Daniel's mother, Inge, did visit often.)

Miller, Abraham, Arrington - none felt they had a choice. To someone like Arrington, who tried to care for her children in the home without any help, a place like the Arizona Children's Colony was a relief.

And over the years, the children grew up. Throughout the '50s, older Coolidge residents were sent to the state hospital or sent, with no place to go, into the community. By 1962, the colony shifted its focus, and the Legislature changed the law to allow residents to stay at the colony after they'd grown up.

Conditions weren't perfect - far from it. In 1977, a class-action suit forced the center to reduce the number of people living there and dramatically improve living conditions.

For a long time, ATPC wasn't a place you'd want a loved one to live. At one time, about 1,200 people were crammed into a facility built for around 300. People slept on cots and sometimes went hours without attention. Faye Arrington remembers it "smelling like an institution." Even the assistant superintendent admits that the only windows that existed were slits placed so high on the wall that residents couldn't possibly see out of them. If the facility were like this today, there would be no question about the need to shut it down.

To help ease overcrowding, two other Arizona Training Program centers opened. One in Tucson could hold 200 people. Another in Phoenix, which came to be known as the McDowell facility, accommodated 145.

Though the new facilities went up in the early '70s, an anti-institution sentiment had been brewing since the '60s. Thanks in part to the civil rights movement, a shift toward community integration began. It's an idea still alive today, though it's not always fully realized in some communities. Even when it is, it isn't always properly implemented (see "Arrested Development," February 18).

In the '70s, the President's Committee on Mental Retardation worked to end institutionalization and, as the conditions at many facilities came to light, people started to keep loved ones out of them.

In 1979, the Arizona Legislature followed the trend and decreed that no one could be newly admitted to ATPC. The push toward community integration in Arizona had begun.

Those were optimistic times for the disabled-rights community. John Hinz, a former director of the Governor's Council on Developmental Disabilities, a well-known activist, and proud father of Missy, a 30-year-old with Down syndrome, remembers those years well.

Hinz now runs a recycling business that employs developmentally disabled adults. He pays them minimum wage - sometimes more - which is much more than they'd make in an adaptive workshop. Since his daughter was born, he's worked tirelessly to learn everything about Down syndrome, everything about the rights of disabled people.

"I've been in it for 30 years. I was a total optimistic idealist 30 years ago with my daughter. She was going to have every opportunity, and she did. She's my pride and joy," he says. "But all the promises [about supports and community integration] made have not happened."

For one thing, though there's been a push to move people out of institutions, group homes haven't always been better. Brian Abery is a community-integration specialist at the University of Minnesota. He is strongly against keeping places like Coolidge open, but acknowledges that an institution can come in any size - including a small group home.

Abery has worked to close down state-run Intermediate Care Facilities for the Mentally Retarded in his home state, but he's done so via a person-based planning method that is uncommon elsewhere in the country.

"You can't think about just closing it down," he says. "You have to think about working with individuals to find a place that meets their

needs and goals."

An essential part of meeting those needs is having enough staff to handle individualized plans for each person and the resources to make sure people go to the best possible place, not just the first open bed. Hinz doesn't think we're there yet.

"In a perfect world, we wouldn't need Coolidge," he says. "There would be enough money to [care for a disabled person] one-on-one."

But there isn't. And that's why, even though he was instrumental in closing down the McDowell facility, Hinz has changed his mind and is now fighting to keep ATPC open.

His daughter was among the first generation of developmentally disabled children who were promised a life of opportunity. Missy is a shining example of what the new generation of disabled children has been able to accomplish with support. She grew up in her parents' house and now lives part time in an adult developmental home and comes home on the weekends. She works full time for her dad. When she was younger, she was the poster child for The Arc, a national advocacy organization for people with cognitive disabilities, and she graduated from a regular high school.

Then Missy grew up. So did thousands of others like her. They're getting old and, says Hinz, we're not ready.

"I'm faced with the realities those [Coolidge] parents are faced with.

Missy will never get bigger or better. We have no long-term programs," he says. "We don't have a place. We don't have a resource."

So Hinz understands and supports the push to keep Coolidge open. There are plenty of people who don't.

The Arc is an advocacy organization strongly opposed to facilities like Coolidge.

Joe Bonanno, the director of The Arc of Arizona, says the people at Coolidge deserve the right to choose where they live and work. (Sadly, it's a moot point for the many Coolidge residents who are not mentally capable of making such decisions.) He says he has no doubt people are well taken care of at ATPC but also says that's not the point.

"It's a nice place to visit, but I wouldn't want to live there," he says.

The Governor's Council on Developmental Disabilities also says it's in favor of closure if the state provides adequate funding to make the transition and promises the money from the land sale will go back to help people with developmental disabilities. (The land can't be sold until 2013.)

Groups such as the governor's council and The Arc often cite the Supreme Court's 1999 "Olmstead Decision," which says states have to put people into community placements with reasonable accommodations when appropriate in order to comply with the least-restrictive setting mandated by the Americans with Disabilities Act.

But, the court also said the state could not force a community setting on people who didn't want it and conceded, "For others, no placement outside the institution may ever be appropriate."

Olmstead was an important decision. It gave people the legal tools to demand community supports - but it didn't automatically mandate the closure of facilities like ATPC. The residents and their guardians still have a choice.

But in the case of most ATPC residents, the guardians are the only ones capable of making any choices.

Take the Arrington twins. There is a world of difference between them

and a person with mild cerebral palsy who lives with support in the community. Darrell and Dorrell have moments of alertness in which they can make eye contact when spoken to, but spend a lot of time appearing catatonic. They never learned to speak or sit upright. They can smile at each other and on a good day can push buttons on a child's toy. But their mom says that's just about all they can do. They could never realistically decide what to eat for dinner or how to spend the afternoon.

Not everyone at ATPC is that limited, but they are the exception to the rule. The kitchen specializes in cooking puréed meals for residents who can't eat without choking. The head chef has devised molds so that the mushy food he serves to those residents looks like food. There's a mold to shape the pea-mush into peas, or create a pork chop out of what looks like darkened mashed potatoes. (If a resident is ever unhappy with his or her food, the kitchen will make something else.)

While Darrell and Dorrell have never lived off-campus, it's hard to imagine a group-home provider taking better care of them. Their older sister thinks they'd probably be dead. At least she knows they're safe at ATPC, and she adds that they are part of a community. They have their little sister, they have each other, and they have caregivers whom they've known for years.

"It's a campus facility. They are free to go - the ones who are mobile - from cottage to cottage. They have barbecues, invite neighbors over. There are boyfriends and girlfriends. It's a family," she says. "It's not an institution. I really resent that."

On a day in early March, it certainly doesn't feel like one.

At midday, the Coolidge residents are all at work or therapy. For those who've reached retirement age, ATPC has created a program to suit their needs.

Residents who can work, do. They earn money by sorting nuts and bolts for a garage door company in Phoenix. ATPC makes sure to accommodate everyone in the workshop according to need - one man who has a history of bed sores has a wheelchair adapted so he can lie down to work, and the staff repositions him often.

At an on-site adaptive workshop, one older woman is having a new wheelchair molded for her. A physical therapist is present, as is a nurse, and they position her just so. Next, the master of the shop - a woman who's worked at ATPC for more than 30 years and knows the contours of each resident's changing body - begins the pour.

A pink liquid fills the space between the woman's body and the back of the chair. It fizzes up behind the plastic that protects her from getting dirty and turns to foam, then hardens. When the chair is done in a couple of days, it will be upholstered and fitted to the contours of the woman's body. It's a great service, and one used often. Almost 50 percent of the population here needs a chair.

In a therapy room, one of the Arrington twins is positioned in a recliner designed to help him stretch. Around him, the lights are low. Being inside the room feels a little like being at a rave - there are flashing lights, lava lamps, and glow-in-the-dark decorations hung at every angle. No matter where Arrington or the other five people in the room look, there is something to keep them visually stimulated.

More than 100 of the people who live here are diagnosed with severe or profound disabilities, and therapy like this is how the staff keeps them active. No one spends all day in any one room. They all go to work, their retirement program, or therapy every weekday.

A tour of several of the living cottages reveals clean quarters, where most clients have their bedrooms decorated however they want (Spider-Man is popular here). Each room feels individualized with photos, some over 50 years old, of family members, and personal belongings such as china dolls (in a glass case) purchased for the residents. The facility just bought a \$10,000, high-tech bathtub to help caretakers bathe their fragile clients. One cottage is outfitted for the sight-impaired. Three-wheeled bikes are parked outside others.

In the living room of one of the homes, a woman named Margie sits at a piano. Margie is thought to have autism, though no diagnosis was made when she was a little girl. If she'd been born today and treated with modern methods, her life could have been much different, staffers say. Margie is probably a genius. She reportedly started playing the piano by ear when she was 2. She can play any song after hearing it once, the staff says. She has a piano at ATPC, but she wants a new one. Hers isn't tuned right, Margie says. The family and friends support group is saving to buy her a replacement.

On that same March afternoon, Margie sits on the bench, fingers poised on the keys. She has quite an audience today - five strangers on a tour and a few familiar faces. She grins and settles in to play.

As her audience quiets down, Margie presses the keys. The song is "Amazing Grace," and she performs every verse perfectly.

In light of how familial ATPC feels, it's easier to understand why parents, guardians - and some others - are so insistent it stay open. Elliot Gory, the psychologist who has worked part time at Coolidge for 30 years, says the clients here are safe. He wonders if it might damage them to move so late in life.

"I get into every nook and cranny. The staff is caring, gentle, and they're skilled. I talk with staff who have known the client I'm working with for 20 years," he says. "There's always the risk of trauma if you relocate someone who is older. There are negative health effects and on top of that, these are people with developmental disabilities who are not resilient. They have difficulty accepting change."

A visit to Hacienda de Los Angeles, the only other large Intermediate Care Facility for the Mentally Retarded in the state, shows a place similar to ATPC. It's newer; one wing was just completed last year. It's also a lot smaller. The facility near South Mountain has 60 beds; 39 are full.

Residents at Hacienda all share bedrooms, most of which are considerably less personalized than the rooms at Coolidge, though no less efficient. The age range at Hacienda is different as well; it has residents as young as 6 and is equipped to take care of babies.

In the early afternoon, all residents are split into small groups to listen to music and work on arts and crafts. The facility has a playground adapted so that even wheelchairs can be placed on the swings.

There's a pool, and a local Kiwanis club funded the construction of an apartment where family members can stay when visiting.

Aside from the location and the number of beds, it's not much different from Coolidge. But no one is trying to shut Hacienda down.

Hacienda's executive director, Bill Timmons, has led the effort at the Legislature to close ATPC.

"I don't think the Coolidge staff are mistreating the residents. I believe their heart is in the right place," he says. "But I also don't believe these Arizona citizens should have to live in a place that's not a community. Secondary to that, it costs so much money."

He does make some good points. Though the core staff at Coolidge has been there a long time, only 12 full-time nurses work there. Timmons, who runs a nurse-registry service, says that's not enough. His registry provides nurses to ATPC sometimes, and he says they often have a hard time covering the third shift and weekends.

He may be biased, but there is some truth to what he says. He also points out the state Department of Health Services licensing violations that ATPC has accumulated over the past few years, even going so far as to put them in a binder for a reporter (though he didn't provide the same information on his own facility).

On the surface it appears to be a lot. Some of the violations are mundane: a door wedged open with a dustpan or too much dust on the fan blades. Some are important but not life-threatening: a resident being fed instead of being encouraged to feed himself, for example.

But others are less disturbing if you know the backstory. In a November 2007 report, DHS inspectors found that the facility "failed to monitor three individuals' fluid intake and output, bowel movements, and failed to provide medical studies (colonoscopy for one individual). Individual numbers 2, 6, and 14 subsequently required hospitalization."

In fact, "Individual 14" died in the hospital.

But the stories the family members tell reveal more than the DHS reports.

"Individual 2" in the DHS report - the one who did not get his colonoscopy and was hospitalized for dehydration - is Dorrell. His mother and sister actually refused the procedure for both brothers, feeling it was too invasive for their delicate bodies to handle.

They also say they know the woman who died.

They don't trivialize her death, but they also know she was quite old and was riddled with arthritis.

After careful review of the report, the line between neglect and natural death is blurry. ATPC was cited for failing to provide adequate physician care, but not for abuse or neglect.

The death of "Individual 14" was the only death cited by DHS in reports dating back to 2005, which is remarkable, considering the average age of the Coolidge residents (most are in their late 50s) and their relatively diminished life expectancy. There are no deaths mentioned that resulted from neglect. That is not the case in Arizona's group homes. In 2007, at least two men died as a direct result of incompetent caregivers: One choked to death on a burrito in front of his attendant; the other hit his head on a wall, with the knowledge of his caregiver, and suffered a brain hemorrhage in bed that night.

Hacienda also has been cited for everything from violating fire codes to violating protection of a client's rights. There are examples of clients who were not positioned correctly for their feeding tubes, or who were not getting enough oxygen.

The similarity between ATPC and other facilities is one that hasn't come up in the Legislature. Of course, one facility is private; the other is run by the state, but according to Brian Abery, of the University of Minnesota, an Intermediate Care Facility for the Mentally Retarded is an institution no matter how you slice it. (For the record, Abery is against nursing homes, too.)

From Abery's perspective, if one has to close, the other does, too.

Much of the focus remains on ATPC's past, and the fact that it is "isolated" from society, as Timmons puts it. It sits in the center of the fastest-growing part of the state.

Deb Henretta, whose brother Vinnie has lived at the facility since he was 15 (he was injured in a car accident), wishes the argument could move beyond whether or not Coolidge is an institution and shift toward finding a way to tap what she sees as an underused resource.

"ATPC serves individuals with the greatest needs and complex medical conditions," she says. "ATPC could fill that need for elderly individuals who have special needs."

In 2002, the U.S. Surgeon General reported that people with developmental disabilities are less likely to receive good health care. Doctors just aren't trained to do it.

The report cites a need for places like Coolidge to figure out how to provide adequate care for a growing population of geriatrics with developmental disabilities, as well as find a way to train healthcare professionals.

One facility, the North Virginia Training Center in Fairfax, is mentioned in the report.

At a cost of \$350,000 a year, it provides critical training on how to care for an aging DD population. There are other centers like it in Massachusetts, Kentucky, New Jersey, Washington State, Florida, and Missouri.

In many ways, the Coolidge center already functions like a nursing home and retirement center. There's even a chapter of the Red Hat Society (a social group for women over 50 in which members wear red hats and purple outfits to their gatherings) on campus. The Red Hats of ATPC dress up in full regalia for their meetings, just as any chapter would.

On posters around Margie's piano room (she's a Red Hatter as well) pictures are displayed from a past meeting. The women are shown looking at themselves, in their outfits, in handheld mirrors. They all look happy with what they see. Another set of pictures shows them gussied up and grinning at a Valentine's dance sponsored by the Red Hat ladies.

In the sensory-therapy room, a place that might make an uninitiated observer squeamish, there is an attendant for every person. When a resident moans, his head is stroked gently. When another laughs as she pushes buttons that make animal noises, her caretaker laughs with her. Across the compound, the retirement center also is busy with activity.

In a colorful room, filled with as many employees as residents, one woman plays with blocks on the floor, while another talks to her caretaker (she's concerned about her waistline).

Sixty miles north of this center of activity, advocates, legislators, and family members continue to struggle with how to make the right decision about Coolidge. In the minds of family members, one fact cannot be disputed: Their relatives have survived long past their projected life spans. When these people were born, they were taken home by parents who expected them to die within a year.

And yet, here they are.

For Deb Henretta, that alone is reason enough to keep her brother in Coolidge.

"We have nursing homes that care for our medically fragile elderly folks. We have programs that offer services to children with special needs. Remember, the children do grow up, they become adults and age," she says. "There is a need now for individuals with developmental disabilities that are aging. Maybe ATPC could fill those needs."

Tamie Hopp

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