

Closing

The End of an Era

Johnstone:

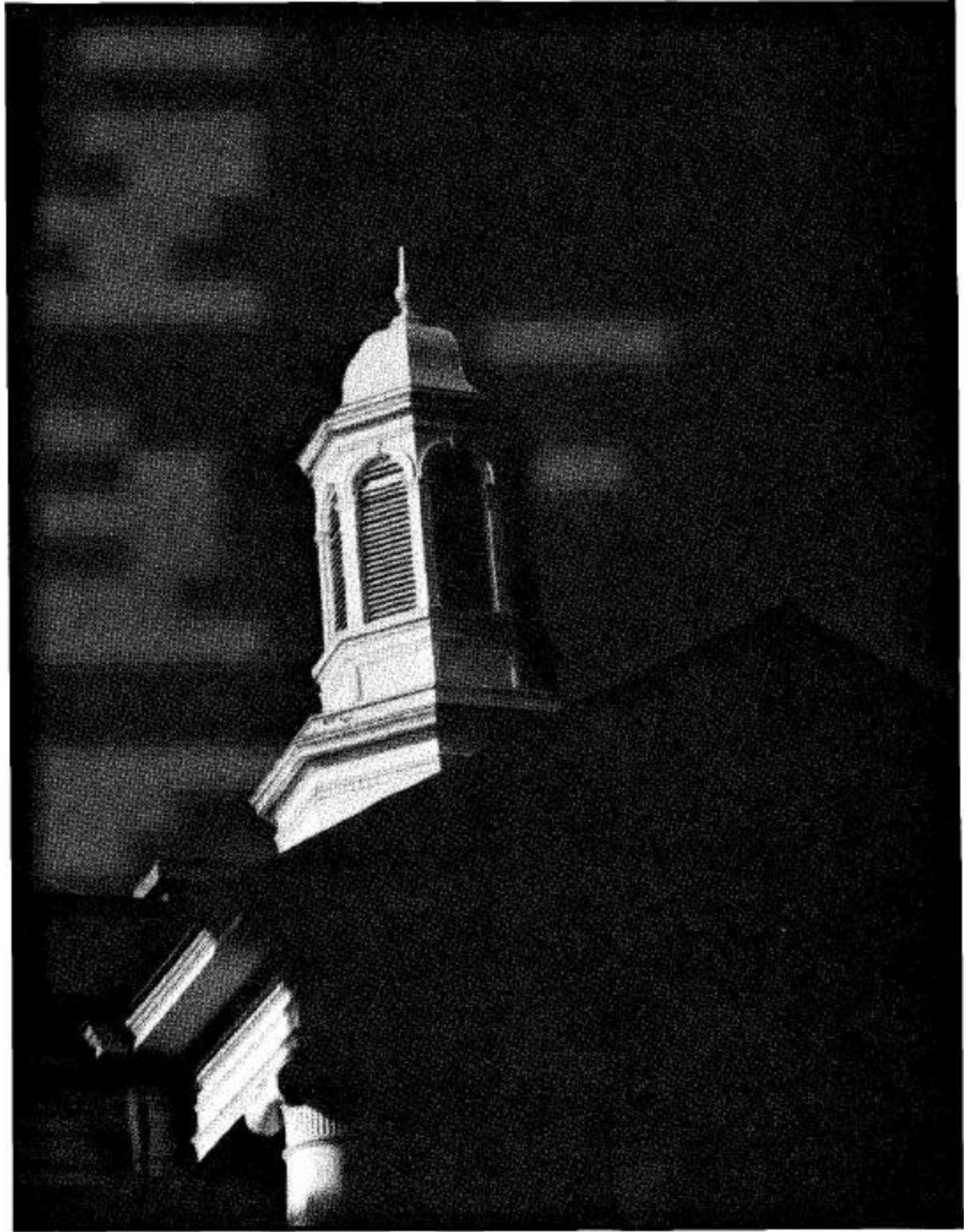
Closing Johnstone: The End of an Era

Published by
The Family Support Network,
The School of Social Work,
Rutgers, The State University of New Jersey,
Dr. Patricia C. Dunn, Director,
with a grant from the
New Jersey Developmental Disabilities Council,
1993

Closing Johnstone: The End of an Era

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THE REAL MEANING OF THE JOHNSTONE CLOSING



This is a work of history, but the people who wrote it were involved in the long and difficult battle it describes. We cannot and do not claim complete objectivity. The best we can do is to identify our biases.

Our purpose in chronicling the closing of the Johnstone Training and Research Center is simple. We firmly believe that all nine of the currently existing developmental centers should be closed—and will be closed—over the next few years.

The Johnstone closing was, by any measure, a success, but it uncovered some serious issues and problems that our community worked around, but did not solve. We want to identify these problems and issues for future consideration. We want to face some uncomfortable truths about our community, because we do not believe they will go away. They could not be solved in the heat and pressure of an institutional closing. Now is as good a time as we are likely to have.

From the beginning various interest groups saw the closing of Johnstone in very different ways. For some of the parents of the people who lived at Johnstone, and other New Jersey institutions, it was an emotional issue. Many of the families saw Johnstone as a safe future for their family members. Aging parents faced the reality that their son or daughter would live on after they passed away—and saw Johnstone as a secure, permanent living situation for people who might be vulnerable living in the community.

Many of these families made the painful decision to institutionalize their family member 20 or 30 years ago, following the advice of doctors or other professionals. This was a corrosive experience and few found it easy to revisit the decision and consider community placement alternatives. They are not to be blamed for this.

There is no question that the Johnstone closing was a painful experience for these parents. There was, among the professionals involved, a tendency to turn away from honestly confronting this pain.

For the staff of Johnstone and the unions representing them, this was the joining of a long expected struggle—the writing has been on the wall for 20 years or more. The days of large institutions are numbered. Other states, one by one, had closed institutions for people with developmental disabilities.

A powerful pro-institutional lobby in New Jersey managed to delay the day of reckoning for New Jersey institutions. The closure of Johnstone, whatever state officials said about it at the time, was seen to be the first of many institutional closures to come. Not surprisingly, the unions decided to put their

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considerable political muscle behind keeping Johnstone open.

Nonprofit developmental disabilities groups were faced with a difficult choice. Most had, for many years, espoused a philosophy of community care for people with developmental disabilities. These same groups were and are the major providers of community services—and were open to the charge that actively supporting the Johnstone closure was simply a matter of their economic interests. At the same time, many of the nonprofits had pro-institutional parents on their boards and in their memberships. Though most of the nonprofits eventually supported the Johnstone closure, it was far from an easy passage for any of them.

The Division of Developmental Disabilities, under the relatively new leadership of Robert Nicholas, had no clear direction on the question of closing institutions. That Johnstone would have to be closed was a budgetary reality—its closing had long been contemplated. The facility was old and would require at least \$15 million in necessary renovations in the near term. Internally, the Division was divided—there were both exponents of the new community services philosophy and supporters of the institutional system.

The Developmental Disabilities Council had both new leadership and largely new membership. Whatever else Ethan Ellis and the newly appointed Council members did, they left little doubt that the Council would no longer be a quiet backwater of the system.

It was an election year, and, not surprisingly, the Johnstone closing became a political issue. Influential parent groups, supported by the union, lined up political opposition to closing Johnstone. Though key players in the political arena continue to strenuously deny any political motivation in their opposition to the closing, the forcefulness of their denials is probably a good index of just how politically charged this issue was. Union members and institutional parents formed a vocal constituency for keeping Johnstone open. Supporters of the closing may—or may not—have had the moral high ground, but they could not deliver any significant number of votes for or against legislative candidates.

There is, of course, one other group of parties of interest. Everyone involved claimed to speak for them. Everyone involved claimed that their interests were paramount. And yet, their voices were rarely heard and less often listened to on this issue, though it affected them far more directly than it did anyone else. We refer, of course, to the people with developmental disabilities served by the system.

One of the most poignant moments in the entire process occurred when Robert Nicholas accepted an invitation to come to Johnstone and speak to this constituency at a self-advocacy group meeting. They were concerned and fearful

about the closing. He explained that he wanted to see everyone living in a real home. One of the participants raised her hand. "What's a home?" she asked, unable to remember ever having lived in one and really wanting to know what he was talking about.

Nicholas's halting and painful explanation of how he and most of the rest of us live was an awkward and beautiful moment within a process that contained few moments admitting that description. It was a moment without posturing. Nicholas lost his personal and organizational defenses and reached out to make a human connection with the people his organization is mandated to serve. It was a moment of truth in a season of heated rhetoric, press releases and letters to the editor. It was a moment of talking with people with developmental disabilities, not for them, not about them.

People with developmental disabilities who live in institutions often reject the notion of living elsewhere—at least initially. Having been isolated from our world, they sometimes have little real sense of what the choices presented to them really mean. We need to listen to them—but we also need to engage them in an ongoing dialogue. If we listen to them, we will surely hear that most never want to live in an institution again after they leave.

There will be continuing opposition to closing institutions. The conflict will be ideological, political and economic, by turns. Families will raise the same concerns that Johnstone families raised. Unions and communities will react to the economic impact of closing institutions.

Occasionally, we will talk about the real issue—helping most of the people with developmental disabilities who live in institutions live in homes, just like the rest of us. That is the way we see it—that is the meaning of Johnstone.

THE JOHNSTONE TRAINING AND RESEARCH CENTER



It took the best part of two years from the initial announcement in the spring of 1991 to the final days in the fall of 1992. The Division of Developmental Disabilities closed the Johnstone Training and Research Center. It was a time of endings for some— a passing of a whole way of life. It was also a time of new beginnings—the opening up of increased possibilities for people who live in New Jersey's institutions for people with developmental disabilities.

Johnstone was a relatively small institution for people with mental retardation. With 229 residents in 1991, it was among the smallest of New Jersey's institutions.

The Johnstone grounds are both extensive and attractive. The oldest build-

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ings were built around the turn of the century, the most recent, in the early 60s. Just across the road, in a building that was once a part of Johnstone, is the Juvenile Medium-security Unit run by the Department of Corrections. This is the only long-term secure facility for juveniles in the correctional system. Johnstone formerly used it as a lock-up for particularly difficult or disturbed residents.

Johnstone is just outside Bordentown, a small, quiet working-class town currently undergoing considerable gentrification with an influx of young urban professionals, many of whom work in Trenton.

The site was originally the home of Commodore Charles Stewart, a naval hero in the War of 1812. The state of New Jersey acquired the property in 1898. It used the property to house the Manual Training School for young black men before turning it into Johnstone in 1956.

Ironically, the state legislature created Johnstone to give young people with mild or moderate mental retardation the intensive services they needed to leave institutions and live in the community. There was a special unit to do research and develop habilitation and teaching techniques. The idea was to come up with approaches that local school districts could use to prevent the institutionalization of other young people with similar disabilities.

By the end of the 80s, the peculiar mission of Johnstone had largely been forgotten. Johnstone was no longer seen as a waystation to the community—it was not a significant participant in the wave of institutional "depopulations" in the 70s and 80s. Cutbacks in recent years had left very little of the research unit in place at the time of Johnstone's closing.

Still, the institutional culture of Johnstone maintained the fiction that it was a "special place." Some Johnstone staff and families of residents believed that Johnstone was a refuge for people with behavior problems who could not be handled at other institutions or in the community. Though researchers found no really significant differences between Johnstone residents and residents of other institutions in terms of challenging behavior, the mythology of Johnstone persisted throughout the closing process.

There were troubling stories about Johnstone. Some involved the continuing use of solitary confinement, long after the Division had outlawed it. Some involved a generally punitive attitude by some of the staff—a use of behavior management to punish, rather than teach. Some Division staff saw Johnstone as a symbol of the old way of doing things and Johnstone Superintendent John Wall as "the last of the old-time superintendents" as one of them put it.

By the end of 1992, the formerly teeming campus was deserted. Weeds were already growing through the cracked asphalt of the parking lots. It was more than the end of Johnstone—it was the end of a whole way of thinking

about people with developmental disabilities—a way of thinking that held that they belong in "special villages" isolated and protected from the community.

Johnstone was also a beginning. After Johnstone, the writing is clearly on the wall for the entire institutional system. It is increasingly apparent that the Division of Developmental Disabilities and the entire developmental disabilities community faces the challenge of coming up with a fundamentally new way of doing business, as the old system passes into history.

THE RISE AND FALL OF THE INSTITUTIONAL SYSTEM

It is difficult to describe institutional life to those who have not experienced it. Johnstone and places like it were built on the assumption that people with mental retardation needed a special community of their own, protected from the outside world.

Institutions replicated many of the activities and services of a small American town. They had their own farms and gardens, fire companies, industries, garbage collection, maintenance crews, clinics, mail service, dining halls, recreational areas and living areas, all set apart from the surrounding community and all run with at least some resident workers under the supervision of paid staff.

You could live your life at an institution and never have any real contact with the outside world. Residents who died at the institution would be buried in the institution cemetery, with a service attended by staff and residents. An institution was a safe place for people with mental retardation to live out their days in a total environment designed to ensure total isolation from the rest of the world. "The only way out of the system was feet first," one veteran staff member told us.

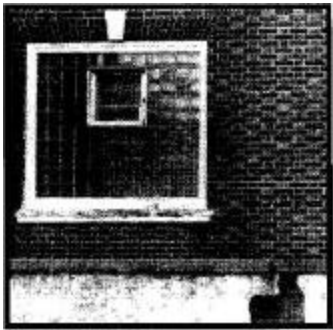
People who remember life in institutions in the 60s or before will remember very substandard conditions. The placid image of the "special village" concealed some stark realities. Staff ratios were unthinkable, from the perspective of 1993. It was not at all uncommon to find a single staff person supervising 50 to 60 people. Institutions were smelly, noisy and dangerous. Physical and sexual abuse were common and nobody talked about those kinds of problems.

Beginning in the 70s, the placid world of the institution experienced growing turmoil as a series of widely publicized scandals and class-action lawsuits began to uncover the real horrors of the system. Geraldo Rivera's expose of Willowbrook on Staten Island was particularly influential—some say that it led directly to the federal "ICF/MR," or Intermediate Care Facilities/Mental Retardation program, to improve standards of care in state institutions.

The ICF/MR program provided federal reimbursements for the cost of care



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In 1978, . . . New Jersey began an effort to take full advantage of the federal program. To meet the standards, it was necessary to reduce the population, increase the number of staff and close units that could not meet the strict physical plant standards.

in institutional units meeting a set of federal standards. If a unit met the standards, the state could claim a reimbursement of 50 percent of the cost from the federal government. This means that a federally certified unit provided better care at far less cost to the state. There was, and still is, a big incentive to meet the federal standards.

The standards require a highly professionalized approach, higher staff-to-resident ratios, enhanced safety, and more privacy and human rights for residents. There are also extensive architectural and health requirements.

In response to the federal standards, institutions generally began a program of modernization. Professional staffs were extensively beefed up. New programs and services were offered. The whole concept of individualized planning for residents was instituted. Teams of professionals developed an individual plan for each resident to use the new programs and services to enhance the development of skills in the individual. Direct care staff ratios were improved by orders of magnitude.

Institutional systems began to shrink—while numbers of staff were actually increased. Research shows that we spend 17 times as much on serving people in institutions today as we did in the 1950s—in real dollars. There is no question that the quality of life and care in institutions has improved dramatically in the past two decades.

This increased staff tended to be better motivated and more highly trained—the ICF/MR standards made extensive requirements on the recruitment, hiring, training and supervision of staff.

DEPOPULATION AND THE GROWTH OF THE COMMUNITY SERVICES SYSTEM

In 1978, late in the game, New Jersey began an effort to take full advantage of the federal program. To meet the standards, it was necessary to reduce the population, increase the number of staff and close units that could not meet the strict physical plant standards. The question arose: Where would the surplus institutional population be placed? The

Division's Community Services system was created to find community placements for the "depopulated" institutional residents. It was never conceived that this system would rival, much less replace, the institutional system. It was, to put it bluntly, a safety valve, not a pipeline.

The role of Community Services staff was restricted to finding community placements for people identified by institutional staff for community placement. There was not—and still is not—a clear, agreed-upon set of criteria for selec-

tion. And, in fact, the original 79 people slated for community placement from Johnstone swelled to 92 by the end of the process, as the Division took a second look at the residents.

Community Services staff had no role in selecting or preparing people for community placement. Institutional staff had no role in following up and supporting the person in his or her new placement.

"It's like two different Divisions," one midlevel staffer told us. "Community Services is isolated from the developmental center system."

Those with least experience in community placement, the institutional staff, select and prepare residents for community placement. Those with least knowledge of the individual involved—community services and provider staff—are left with the difficult task of supporting the transition to a community setting. The community services and institutional systems were not integrated or coordinated within the same overall framework.

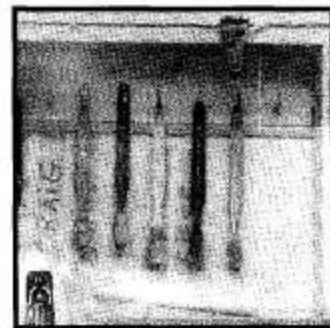
From the beginning, the community services system was dominated by an institutional perspective. The system, to the extent that it was shaped by any conceptual framework, was built on the "readiness" model. This model held that institutions would provide life skills training to individuals to prepare them for community life. These individuals would be placed after they had demonstrated that they were "ready."

The readiness model has been thoroughly discredited—and we need not repeat the entire argument here. It simply does not work, for several reasons. Institutions cannot effectively teach the skills of independent life. Many people who live in the community do not possess all of the necessary skills—their deficits can be made up by their support systems. Those people who live in institutions who truly want out are likely to be seen as difficult and noncompliant—and not "ready" for community placement.

Though the readiness model is no longer given official credence, the fact remains that the whole approach to community services within the Division was based on it. And, by and large, institutional staff who select people for community placement still hold onto it—if only because it has not been replaced by anything else.

The readiness model was also partially responsible for the system's reliance on group homes as the primary form of community placement. The group home was seen as a logical next step in a hierarchical system. Those who proved themselves in a group home program would move on to supervised apartments—and then to supported living programs. It was tacitly assumed that most would remain in group homes.

In the 80s, Community Services suffered under the various job freezes and



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budget cuts. Caseloads reached unrealistic levels. Despite the success at Johnstone, this was not and is not an organization ready to meet the challenge of closing New Jersey's entire institutional system.

The depopulation programs of the 70s and 80s established a pattern. Many of the people "depopulated" from institutions entered New Jersey's community system. Others, thought not ready for community placement, were transferred to other institutions. This same pattern was followed in the Johnstone closing.

Opposition to closings of institutional units did not begin at Johnstone. The original depopulation program was opposed by the Public Advocate and greeted with skepticism by Arc/NJ, the major parent group and advocacy organization. Arc/NJ finally accepted depopulation primarily because it improved conditions in institutions, not because it got people out of them. Organized parents blocked all serious discussion of closing institutions right up until the Johnstone closing was announced.

What the Division did to bring Arc/NJ and other nonprofit groups on board left the system with another destructive legacy. Eddie Moore, the former Division director, began a practice of contracting with the Arc and other nonprofits to provide group homes. The major parent group and advocacy organization became the major provider of services in New Jersey. The Division created financial incentives for the nonprofits to become service providers—and made it possible for them to build extensive professional and advocacy staffs with state money.

These financial incentives favored capital-intensive programs. The Division wanted group homes—and it got them.

We entered the Johnstone era with a community services system with severe structural and administrative problems, lacking a clear vision of the future role of community services in the service system, driven by outmoded philosophies and dominated by a reliance on group homes as the placement of choice in the community. We entered the Johnstone era with the large nonprofit parent groups dominating the community services market and with community group homes as the placement of choice. None of these problems were solved at Johnstone.

They must be solved before the process of closing institutions proceeds.

A NEW DIRECTION



In the 70s and 80s, the service system was shaken by fundamental changes in how people viewed people with developmental disabilities. The new community programs led professionals to revise their

opinions of the capabilities of people with developmental disabilities. It became apparent that the large majority of institutional residents could live productive, relatively independent lives in the community.

What happened, we believe, is that people with developmental disabilities were finally put into situations which allowed them to prove that they could *exceed* the expectations placed on them in the past. Professionals and advocates began to question the wisdom and justice of isolating people in the "special village" and limiting their opportunities to be full citizens, with jobs and homes of their own. For many the "special village" became a plantation or a gulag—a place where people are isolated and confined, not protected.

This point of view was shared by advocates, young professionals and an increasing number of people with disabilities themselves. The rise of the self-advocacy movement—people with developmental disabilities speaking for themselves—reinforced the message. Many self-advocates became outspoken critics of the institutional system.

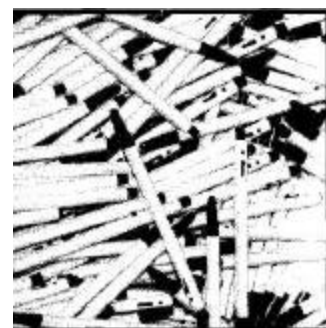
We discovered that the isolated environment of an institution is a problematic place to teach people how to live independently. A growing number of professionals and consumers saw no real rationale for institutional placement for the vast majority of institutional residents. Successful community programs demonstrated that former institutional residents could become productive citizens.

During the last decade, states around the country have been closing institutions and moving institutional residents into community programs. Though New Jersey's institutional population has declined, the state has not kept pace with the national trend. In fact, experts have speculated that New Jersey is now number one in the number of people with developmental disabilities in institutions, if you adjust for population.

Rising costs were as much a factor in closing state institutions as changing philosophies. Institutional costs are spiraling. It is reliably estimated that it will cost \$113,000 in real dollars to provide institutional care for one person for one year in 2000. Examining this economic scenario, many states have decided to get out of the business of institutional care while the getting is good. A few closed all of their institutional beds. It was widely accepted that this was the wave of the future.

New Jersey had not turned this corner. On the eve of the announcement of the Johnstone closing, public statements from the Division repeatedly reaffirmed a strong commitment to the future of institutions. Johnstone would change all that.

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A SHORT HISTORY OF THE JOHNSTONE CLOSING



n February 16, 1991, the New Jersey Governor's Office released its proposed budget for the 1992 fiscal year. The budget was carefully reviewed by a host of agencies and interest groups. Given the grim economic situation in the state at that time, many of them expected bad news.

For those with a vested interest in the institutional system run by the Division of Developmental Disabilities, the worst possible expectations were fulfilled. The budget announced that Johnstone Training and Research Center in Bordentown, New Jersey would be closed.

The announcement of the Johnstone closing was made without prior discussion within the developmental disabilities community, as even Robert Nicholas, the Division director, did not know definitively that the institution would be closed until the night before the Governor made the announcement.

It has since been said by many observers, including several key legislators at subsequent budget hearings, that the announcement of the Johnstone closing was not handled well. Parents, especially, resented the lack of advance notice and the opportunity to participate in a community forum. And yet, it is unlikely that the announcement was a complete surprise to the leadership of the parent group at Johnstone.

Nicholas recalls that within two weeks of his appointment in May 1989, he had a meeting with a Johnstone parent group on plans to close this facility. "I was able to tell them that we were withdrawing the five-year plan that called for the closing," Nicholas says. "I was careful, however, not to make any commitment to Johnstone's future. It occurred to me that Johnstone would probably be closed eventually, and I did not want to give a false impression."

In fact, the closing of Johnstone had become a perennial issue around budget time. Plans for phasing down or closing Johnstone had been around for years. The Division had embarked on a program to reduce its institutional population. By 1988, it was already getting to the point where further reductions would realistically require closing an institution. For several reasons, Johnstone was the logical choice.

In the first place, only 40 of the 229 people at Johnstone lived in units meeting the federal standards. Closing Johnstone would be a real step toward closing noncertified units. It could be argued that the closing was in keeping with the consensus in the community that these units should be closed.

The physical plant at Johnstone was decaying. The Division estimated that it would cost from \$15 million to \$20 million to make Johnstone livable. In addition to a major renovation of most of the buildings, Johnstone would have

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needed extensive work on its heating plant, steamlines and roads.

Given that the Division was committed to reductions in the institutional population, it made little sense to invest so heavily in any institution.

The Johnstone parents group, Friends of Johnstone, asserted that Johnstone could be kept open for far less. This was also probably true, but such a strategy merely postponed an inevitable decision. Eventually, we had to decide either to close the institution or to make a long-term capital investment in fixing it.

This decision had long-term policy implications. Division analysts told us that a major investment in the institutional infrastructure would spell the end of the 13-year trend of declining institutional populations.

A Division staff member remarked at the time that, "We are already too dependent on institutional services. Spending money on Johnstone is just buying more heroin . . . The consequence will inevitably be that people will stay in institutions who should be in the community and people in the community will end up in institutions instead of community programs. We can't afford to spend money on fixing Johnstone and then not use it to its fullest capacity."

In the early days after the announcement, the decision had many enemies and few supporters.

Families with children at home or in the community were either indifferent to the closing or opposed it because they feared it would drain resources from waiting list initiatives and community services generally. Many still hold this point of view and are very angry to see community placements going to institutional residents when many people who chose to keep their son or daughter at home face real emergencies.

Arc/NJ was embroiled in a severe internal conflict. Professionals supported the closing. Parents did not. The new executive director, Paul Potito, had a serious problem on his hands. His parent boards were in virtual revolt on the issue.

The other nonprofits initially took the view that they did not have a compelling interest one way or the other. This was a fight that would largely be within the large community of those concerned with and about people with cognitive disabilities. They were reluctant to get involved, though most supported institutional closings.

In March of 1991, less than a month after the initial announcement, 300 angry parents, workers and Johnstone residents gathered outside the Department of Human Services in Trenton with signs and banners. The parents group, Friends of Johnstone, announced a lawsuit to stop or delay the closing.

In April, the Developmental Disabilities Council voted to adopt a formal

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position statement on the Johnstone closing. The vote was unanimous. Behind that vote was a clear message that the Developmental Disabilities Council had changed its membership and intended to take the lead on this issue.

The Council's statement expressed strong support for the Johnstone closing, but also compassion for the feelings of the families of Johnstone residents facing a period of painful change. A number of the Council members had sons or daughters with disabilities. They were familiar with the agonizing choices faced by Johnstone parents, both in placing their child in an institution and in facing the prospect of a community placement.

At the same time, the Council voted funding for the Family Support Network at Rutgers, a project to help Johnstone families through the closing by providing information and self-help.

Those fighting to keep Johnstone open responded to the Council statement with fury. Robert Angelo, then an official of AFSCME, called the Council "a rubber stamp" for the administration and suggested that its support for the closing was motivated by economics. Ed Warshawer, one of the leaders of the parents group, said, "I have no words to describe what a terrible decision this is."

Various nonprofit groups followed suit, including the Arc of New Jersey. Opponents of the closing were enraged. They distributed leaflets and wrote letters accusing the Arc, as the largest provider of community services, of a conflict of interest. They suggested that the Arc was voting its economic interests.

Arc/NJ support for the closing was a near thing and probably did not represent the opinion of a majority of the members. It was engineered by Frank Nardi, newly called back to the presidency by the new Arc/NJ director, Paul Potito, and Potito himself, with the support of the county executive directors, their professional staffs and a few board member parents.

Pro-institutional parents within the Arc put considerable pressure on the organization to back away from this stand throughout the process.

Other advocacy groups found themselves in the middle of a similar struggle, since most are also providers of community services. The community became incredibly polarized.

In the end, the community held together on what was, for most, a matter of principle, when all was said and done. The nonprofits had been pushing for deinstitutionalization for years. When the time came to support the Johnstone closing, they could easily have backed away rather than face internal conflicts with pro-institutional families and external charges of conflict of interest. They bit the bullet and publicly supported the closing of Johnstone.

Throughout the Johnstone closing, an informal group of advocates met with high-level Division staff to make sure that the closing would go forward, and that the Division would keep its promises. This group, called the Johnstone Breakfast Bunch, held early morning meetings at the home of Ethan Ellis, the director of the Developmental Disabilities Council. This group served a valuable role in coordinating the process. They began by planning the strategy to defend the decision to close Johnstone and moved on to address the inevitable problems and issues raised during the closing. Oddly, through the Breakfast Bunch, the Johnstone closing may have done much to increase cooperation and trust within the developmental disabilities community.

In addition to identifying and solving problems encountered during the closing, the Breakfast Bunch became a forum for talking about serious ongoing issues.

One ongoing discussion involved the IHP process and family involvement in it. It emerged that families' perceptions of the IHP are very different from those of Division personnel. Families were only dimly aware of the IHP—in fact, a recent survey of families on the community services waiting list conducted by Professor Paul Lerman of Rutgers shows that well more than half of the families surveyed were totally unaware of any plan or objective for their family member. Few felt that they were meaningfully included in any kind of planning process.

The Johnstone families had similar feelings about the IHP. Few felt meaningfully involved in making decisions about their family member.

Friends of Johnstone waged a campaign to keep the Johnstone story alive throughout the spring and summer of 1991. Ethan Ellis set off a particularly bitter exchange when he wrote, in a June op-ed article, that state funds should not be funneled down "the Johnstone rat hole." Though Ellis was referring to the notion that further money should not be spent on an antiquated facility, staff and parents took considerable offense at his words. John Wall, the Johnstone superintendent, appeared at a picnic with a T-shirt emblazoned with the defiant words: "King of the Johnstone Rat Hole." There were dueling letters on the editorial pages of New Jersey newspapers.

The battle raged at the hearings of the legislature's budget committees. Competing sets of witnesses supported and opposed the closings.

Throughout the process, AFSCME, the union representing institutional workers, maintained a hostile stance toward those supporting the closing. Union staff met with and provided direct assistance to the parents group, Friends of Johnstone. Union leaders made statements attacking the community services system. They suggested that the advocacy organizations supporting the closing were, as providers of community services, only interested in increasing their

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The arguments for the closing focused on the long-term need to close institutions and return institutional residents to productive lives in the community.



share of the market. They issued statements defending institutional care and rejecting the goal of community integration for people with developmental disabilities. In so doing, AFSCME created a legacy of bitterness among advocates for people with developmental disabilities that continues to this day.

"We do not mind them aggressively pursuing the interests of their members," one community leader commented privately, "but we will not allow them to do it on the backs of our constituents."

The arguments for the closing focused on the long-term need to close institutions and return institutional residents to productive lives in the community. Opponents of the closing pointed out that relatively few Johnstone residents were being placed in the community—most were being transferred to other, larger institutions.

Some families expressed considerable reservations about the quality of community residences. They were particularly concerned about placements in so-called skill development homes—foster homes for people with developmental disabilities. There are continuing concerns about the training of skill development providers and the monitoring of the homes.

Unfortunately, the families also mounted attacks on group homes and other community services provided by the Division. The general concern was that community placements represented an abandonment of former institutional residents in the community, that appropriate supervision and services would not be provided.

Some of the testimony at hearings raised arguments for keeping Johnstone open that rested on the nature of the Johnstone population. During the debate, family members and some Division professionals said that Johnstone residents were the most behaviorally challenged in the system. It was said that many had had unsuccessful placements at larger institutions. They were said to be poor candidates for both community placement and transfer to other institutions.

Opponents to the closing also focused on the small number of Johnstone residents with visual impairments and physical disabilities. It was suggested that these people, mostly residents of the Hayes Unit, needed the protected environment of Johnstone and would not fare well elsewhere. They were not thought to be good candidates for community placement.

Some of the concerns expressed by parents and lawmakers arose from a lack of knowledge. In interviews with parents at the time, we repeatedly encountered people who thought that group homes did not have staff available at night. All of them had heard horror stories about failed community placements—they had never been exposed to the many people with developmental disabilities who have made a successful adjustment to living and working in the community.

They had never heard from the many families that are satisfied with community services.

Some families and lawmakers were clearly confused about the history of deinstitutionalization in the Division of Developmental Disabilities. They made repeated references to the mental health system and the abuses that resulted from the closing of mental hospitals in the 70s. They seemed unaware that the Division had virtually halved its institutional population—without similar problems and with a minimum of publicity. These references continued in statements by and interviews with legislators well after the Johnstone closing.

Assemblyman Rodney Frelinghuysen, widely regarded as the most knowledgeable legislator on these issues and a staunch supporter of community services, opposed the closing, referring to it as "another blunder by the Florio team."

Assemblyman John Watson, a Democrat and chair of the Assembly's Appropriations Committee, met with the Friends of Johnstone, toured the facility and repeatedly announced his opposition to the closing.

Both parents and lawmakers repeatedly noted that the group homes and other community placements required did not exist. They felt that Johnstone should not be closed until the placements were available. The Division responded that, given funding, community placements could be created. The argument quickly became a matter of trust—parents did not believe the Division's statements. "There is no plan for closing Johnstone," was the often repeated refrain from the Friends of Johnstone.

The effect of the Johnstone closing on the prospects for placement of people on the Division's waiting list provided another divisive issue. Many parents felt that the focus on placing people displaced by the closing would delay the placements of people living in the community. Since these placements are often emergencies—aging parents who can no longer provide care in their home—this was a deeply felt issue.

The Division said that the Johnstone process would have no effect on others awaiting placement, but this concern was not laid to rest. In the end, it seems that Johnstone had, indeed, little impact on the people from the waiting list.

The fate of Johnstone employees was a hot political issue. Early in the process, the Division promised to place all Johnstone employees in other jobs. The union questioned their ability to do this—and, indeed, their real intent. As far as we can determine, the Division also kept this promise. The former Johnstone employees we have interviewed recently are not uniformly happy about their new jobs, but they do generally feel that the Division kept faith with them.

The political situation during the Johnstone debate could be confusing. On



Some of the testimony at hearings raised arguments for keeping Johnstone open that rested on the nature of the Johnstone population. . . . They were said to be poor candidates for both community placement and transfer to other institutions.



The Division made a commitment that is unprecedented in the history of institutional closings. As part of a research project funded by the Developmental Disabilities Council, Conroy & Feinstein, a Pennsylvania-based research firm, would be evaluating the impact of the closing on all residents.

one occasion, a candidate assured a disability advocacy group that strongly supported the closing, "I support services for people with mental retardation. I oppose closing Johnstone." Several legislators approached legislative advocates for disability organizations with the complaint that the disability community needed to make up its mind on the Johnstone issue.

There were, indeed, serious internal conflicts among disability advocates around the closing. Many of those who support closing institutions want to see all of the people who live in them placed in the community. The closing of Johnstone made it possible to place about 190 people in the community. The Division chose to place people already identified for community placement from all of its institutions, rather than placing Johnstone residents exclusively.

There was a pitched battle at the informal "Breakfast Bunch" meetings over institutional transfers. Arc/NJ was particularly adamant in its stand against them—to the point that the Arc's continued support of deinstitutionalization was called into question.

Robert Nicholas continues to defend this decision. "I cannot think of a single institution we run where you could place all of the residents in the community services currently available to us," he said in a recent interview. "If you are going to insist that we wait until we are able to serve all institutional residents in community services before closing an institutions, that will be a major barrier to the process of changing the Division from an agency that runs institutions to an agency that serves people in the community."

In July 1991, the Johnstone debate heated up again. The legislature passed a budget that included a \$4.5 million appropriation to keep Johnstone open. On the first of the month, just six minutes before the state treasury would have officially run dry, Governor Florio signed off on it. He used his veto to cut \$2 million from the appropriation for Johnstone, sending a clear signal that the administration intended to stand by its decision. The Friends of Johnstone hardly had time to celebrate winning the budget battle before it became clear that they would lose the war.

Later in July, the press carried stories on the forced retirement of John Wall, the superintendent of Johnstone. Wall had opposed the closing publicly. He had become a symbol of the opposition to the Johnstone closure—and, in a way, a symbol of Johnstone itself.

Wall's departure was a major landmark in the history of the closing. Though opposition remained strong, most opponents accepted the fact that Johnstone would close.

In December 1991, there was a brief revival of the Johnstone story. Assemblyman Watson held hearings to monitor the Division's plan for closing the

facility. A by-now familiar cast of characters made essentially the same statements that they had been making for nearly nine months.

The argument was as bitter as ever. There was a particularly sharp exchange between Colleen Fraser, the Council chairperson and Watson, when she suggested that the hearing was politically motivated.

The hearing ended with no clear action. Watson said that he might consider asking the governor to keep Johnstone open indefinitely if the closing did not proceed smoothly. To all intents and purposes, the public debate on Johnstone was over.

After that, things got pretty quiet. One by one, the buildings at Johnstone closed as residents left. At the end of September 1992, the last person left and the doors of Johnstone were locked.

THE ORIGINAL PLAN

The Division's original plan for closing the Johnstone site was complex. Seventy-nine of the 229 current residents at the institution would go directly into community placements. The remaining 150 would go to other developmental centers around the state. Fifty-seven of these would be going into small group homes on the grounds of North Princeton Developmental Center. These homes serve as "transitional residences" for people awaiting community placement. At the same time, 150 people from other developmental centers would be placed in the community to make up the total of 229 institutional beds lost to the system with the closing.

All placements of Division clients are governed by the findings of each person's "IHP," or Individual Habilitation Plan, an individualized plan drawn up with input from professionals, family members and the person involved. The 229 people going into the community as a result of the closing were all slated for community placement—and many had been for quite some time.

Dr. Nicholas maintained throughout the process, that even those Johnstone residents going to other institutions would benefit. Speaking in an interview at that time, he said, "Those residents who will be staying in the institutional system will get placements that are at least as good as what they had at Johnstone. Most of the people at Johnstone currently live in units that do not meet federal standards. All of the new placements will be in federally certified units. That means more staff, better conditions and more safety. Only 40 Johnstone residents will be moving from a federally certified unit there to a federally certified unit elsewhere."

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The other institutions that received Johnstone clients currently do not report major behavior problems occasioned by the transfer.



institutional closings. As part of a research project funded by the Developmental Disabilities Council, Conroy & Feinstein, a Pennsylvania-based research firm, would be evaluating the impact of the closing on all residents. Conroy & Feinstein would be using standard measures to assess quality of life and consumer satisfaction.

The Division promised to take corrective action if this study disclosed that any client had suffered a degradation in his or her quality of life as a result of the Johnstone closing.

Dr. Nicholas and the Division made another important commitment several times—though it seems to have done little to resolve the fears of Johnstone parents. Nicholas said that the Division would not place any Johnstone resident until "a suitable placement that meets the resident's needs is available." Questioned at the budget hearings if that meant that Johnstone would remain open until such placements could be found, Nicholas replied, "Yes."

Dr. Nicholas also attempted to reassure Johnstone staff members that they would not be left without jobs as a result of the closing. Sources in the Division claimed that these statements amounted to a guarantee that Johnstone staff would be protected from layoffs affecting employees in other institutions. "You could say that the Johnstone people are pretty lucky," one Division staff member remarked.

Given all these promises, it may seem surprising that some Johnstone staff and parents continued to oppose the closing so strongly. One parent dismissed the Division's promises completely.

"People just don't trust the government, I guess. It's too bad, but you can see why. Government has made so many shabby deals. We tend to think that the promises they make won't mean much once things have died down, that they're only making them to shut us up. That's how things are."

The Division gave full attention to potential problems at Johnstone. A "war room" was maintained at the Division's central office in Trenton, with up-to-date information on the progress of the closing and the destination of each client. Senior staff were able to give direct attention to any problems that occurred and to clear up any logjams in the placement process. There was an ongoing attempt to respond to concerns about any of the specific concerns raised by parents. Staff were kept busy running down and "zapping" rumors.

The Johnstone management team divided the responsibility for running and closing the facility. Paula DiVanuto, the superintendent, kept the program running. Phil Conti acted as a direct overseer to the process of writing IHPs for each of the residents and developing placements.

Conti also met, on a regular basis, with a group of representatives of parent

organizations from the institutions. He listened to their concerns and made sure that any questions they had about the process were answered.

Throughout the closing, the Family Support Network, a project funded by the Developmental Disabilities Council, provided information and support to parents. The group developed a notebook to help parents prepare for IHP meetings and provided direct support to parents at such meetings. The group published a series of newsletters providing useful information to the Johnstone families.

These groups managed to address any problems that came up. Real issues were discussed at the ongoing Breakfast Bunch meetings. This network of formal and informal organizations is largely responsible for the relative success of the closing—though the management team deserves high praise for their efforts at Johnstone.

The point is that we did not solve any of the underlying structural problems. We simply developed an approach to fixing problems on a case-by-case basis.

WHAT HAPPENED TO JOHNSTONE RESIDENTS?

Each Johnstone resident had an Individual Habilitation Plan meeting to determine his or her new placement. This activity took up much of the year prior to the closing.

The Division put forward a special effort, detailing Phillip Conti, a member of the Johnstone management team, to oversee the process. It paid off. There were only three appeals of the plans by families, and two were quickly settled.

In the end the original plan was greatly modified. Altogether, 92 of 229 Johnstone residents were slated for the community—and the balance to other institutions. Two of those transferred to other institutions were quickly "depopulated" into community group homes.

The movements were not without problems, though far fewer than projected by early critics of the process. There were, as might be expected, a small number of "blown" placements. Two people ended up in psychiatric facilities—and the Division has moved quickly to make sure that they do not stay there longer than necessary. There were some behavior problems in new placements.

An undertaking like the closing of an institution exacts this price. It is not to be expected that a large number of institutional residents can be transferred to other placements without some degree of disruption. It is generally agreed that the disruption occasioned by Johnstone was not particularly severe.

The other institutions that received Johnstone clients currently do not report major behavior problems occasioned by the transfer. Institutional staff make the

A third research report compared institutional residents with people served in the community. . . . The surprising result was that those who remained in institutions were much more similar to those who had been moved to community placements than anyone had anticipated.



Almost all of the families saw significant improvements in their family member's quality of life . . . This was not surprising in the cases of those people who moved to community setting . . . What was surprising was that only 2 of 28 families of people transferred to other institutions thought that their family member was worse off after the transfer.



point that some residents had behavior problems at Johnstone—and still have them in their new settings.

One subgroup of the Johnstone population deserves special mention. Many of the persons with visual impairments and physical disabilities who lived in the Hayes Unit are currently living in the community and working in competitive employment. This group, said by the opponents of the closing to be inappropriate for community placement, is flourishing. None express any interest in going back to Johnstone.

THE RESEARCH FINDINGS: CONROY & FEINSTEIN



Throughout the Johnstone closure and beyond, the Developmental Disabilities Council has funded Conroy & Feinstein, a Philadelphia-based research firm, to study some of the key issues raised by the process.

In 1991, Conroy & Feinstein completed a major study on the New Jersey system of community services for people with developmental disabilities, based on extensive interviews with system stakeholders. The results were no surprise to many long-time observers of the system.

In essence, the researchers found fundamental structural and administrative problems in the Division's approach to community services. The key problem was that community services and institutional services in New Jersey were virtually separate systems, with very poor communications. The implications of this for the closing of an institution were obvious and dire. The report called into serious question the Division's ability to place the large number of institutional residents entering the community in the wake of the closing on a rational basis.

The report challenged the process of selecting institutional residents for community placement. It suggested that the criteria for such placement needed careful study and discussion. At the time, the community system had been seen as appropriate only for very high-functioning clients who were considered "ready." This "readiness" model had not been replaced by a more inclusive approach.

A second study addressed a specific issue raised by opponents of the Johnstone closing. It had been said, a number of times in the public hearings on the closing, that Johnstone residents were the most difficult and behaviorally troubled group in the institutional system and were therefore the least appropriate candidates for community placement. Parents and some Division professional staff suggested that Johnstone residents, because of their behavioral issues, would respond poorly to being moved to "larger institutions." These

arguments were raised, again and again, on editorial pages and at public hearings. Conroy & Feinstein found that the concerns were not well founded. Their study showed that the Johnstone population was younger and higher functioning than average. They were average in terms of challenging behavior. In fact, they were among the best candidates for community placement—and could be expected, in general, to adapt well to any new placement.

The study did raise, once again, the serious question of whether it was justifiable to place so many Johnstone residents in other institutions, since they should be good candidates for the community. While recognizing that institutional transfers may have been an economic necessity for the the Division, the report suggested that it would have been preferable if every Johnstone resident had entered the community system.

At the very least, the second research report confirmed the wisdom of the Division's choice of Johnstone for closure.

A third research report compared institutional residents with people served in the community. This report was seen as crucial in the development of ongoing policy on closing institutions. It would tell us if there were enormous differences in the two populations. If there were, this would suggest that many institutional residents might not easily be placed within the current range of community settings.

The surprising result was that those who remained in institutions were much more similar to those who had been moved to community placements than anyone had anticipated. The research found that there were only about 1500 people living in institutions who were not similar to people currently living in the community. This suggests that most institutional residents could fit into currently available options—but that the Division should focus on the needs of the 1500 people with the lowest levels of adaptive behavior.

Surprisingly, from what we know of research on other residential populations, institutional residents did not show more serious problem behaviors than their counterparts in the community. This flies in the face of conventional wisdom in the professional community. It had always been thought that those served in the community represented fewer behavior problems, and that people stay in institutional settings largely because of such problems.

The report draws the conclusion that "... people of practically all levels of disability can move successfully to community settings." It goes on to suggest that "... those who have benefited most from community placement have often been those with the most severe impairments and the most urgent needs."

Some of the results were far less astonishing. Measures of quality of life and integration showed that people in the community have significantly improved



It is fair to say that the debate over Johnstone was too often conducted with myths, rumors and anecdotes as sources of information. Much of what was said emerged, on careful study, as misinformation.



The issues are simple and obvious: who are they, what do they need and how can it be provided to them—and where. We need to approach these questions without making a lot of assumptions.

quality of life, and many more opportunities for interacting with other citizens. This report encourages the continuing development of community placement efforts. It suggests that, rather than attempting to identify those who can benefit from community placement, the Division should mount an effort to identify those who cannot be served within the current range of community services—with a view to extending that range to include them.

A fourth and final research report answers what has to the major question about the Johnstone process. Was it a success? Did the Division keep its promise to make sure that every Johnstone resident would have a placement at least as desirable as his or her placement at Johnstone?

It would obviously not be possible to answer those questions definitively. What the study did was inquire into the thoughts and feelings of a sample of family members about Johnstone—and about the new placements.

The results were stunning. Almost all of the families saw significant improvements in their family member's quality of life. This was not surprising in the cases of those people who moved to community settings—previous research shows that families of former institutional residents are nearly always more satisfied with a community placement. This was true of all of the Johnstone families surveyed.

What was surprising was that only 2 of 28 families of people transferred to other institutions thought that their family member was worse off after the transfer. Most were more positive about the new institutional placement.

The Division has kept its commitment to follow up with the two families who felt that their family member's quality of life had worsened. Neither of these cases involved serious allegations—one of them was clearly a holdover from the Johnstone battle. Efforts are being made to address any problems identified by the family members involved.

Overall, the Conroy & Feinstein reports give some very useful direction for future policy development. It is interesting to note that the data contradicted a good bit of conventional wisdom about Johnstone, its residents and what would happen when it closed.

It is fair to say that the debate over Johnstone was too often conducted with myths, rumors and anecdotes as sources of information. Much of what was said emerged, on careful study, as misinformation.

Specifically, Johnstone was not a particularly good place to live. If it had been, it is hard to see why family satisfaction increased when family members were transferred to other institutions. Nor were the Johnstone residents a particularly inappropriate group for community placement—they were and are good candidates for the community. And, finally, the closing of Johnstone has

not created tragedies, as far as we can see, so much as it had created satisfied customers.

THE REMAINING ISSUES

In the beginning of the Johnstone closing, the Division had a commitment to close noncertified units in institutions. In public statements, Division officials always made long-term commitments to institutional care. As a result of the Johnstone process, that changed.

Today, there is a general consensus at the Division and among most professionals in the field that, sooner or later, the institutional system will be dismantled. The only real argument is over the timetable. The leadership at the remaining developmental centers is trying to send both staff and residents the message that the institution should not be viewed as permanent.

Though it would be naive to expect that the next developmental center will be closed without a fight, the writing is on the wall. Institutional care has a very limited future. The message to institutional parents must be that the secure future they want for their son or daughter is not to be found in the institutional system. It is to be found in the community. Johnstone resolved this issue.

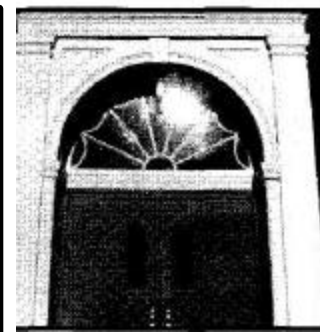
Johnstone uncovered, but did not resolve a range of other issues. By and large, these issues cannot be resolved in the middle of a crisis. We should not wait until they arise again when the next institution is closed. We should address them now.

The Current Range of Community Services

The arguments raised by the Johnstone parents cannot be dismissed out of hand. Time and again, they raised the question of the future of those institutional residents who, apparently at least, do not fit into the current range of options in community services.

The issues are simple and obvious: who are they, what do they need and how can it be provided to them—and where. We need to approach these questions without making a lot of assumptions.

This, too, is a legacy of the Johnstone closing. One of the things we learned is that some people, who have been thought by many not to be able, can live and work in the community. We must not close our minds to this lesson. That the current range of community services is not appropriate does not mean that this population cannot be served in the community.



The institutions will close, if only because we will be unable to afford their continued existence. If the unions choose to stand against their closing, they will miss the opportunity to participate in planning the transition.



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Institutional Transfers

It is evident that any institutional closings that occur in the future will likely involve transfers of clients to other institutions. This is an issue that divided the community during the Johnstone closing and it will only get worse as time passes.

The Division still maintains that none of the remaining developmental centers can be closed without some institutional transfers. This seriously endangers the future support of ARC and other advocacy organizations for institutional closings.

The Future of Institutional Workers

It would also be unrealistic to expect that the Division will be able to go on closing institutions and placing all of the displaced staff in jobs within the system. The Division deserves credit for keeping faith with the Johnstone staff. That does not alter the fact that, at some point in the process, there will have to be reductions in staff. It would be well to plan the process now. Advocates for people with developmental disabilities are not hostile to the interests of institutional staff. It is generally felt that the Division has an obligation to retrain them and help them find new jobs, as institutional jobs disappear.

At the same time, the unions that represent these employees need to accept the reality that institutional care has no long-term future. Throughout the Johnstone process, the union displayed a complete unwillingness to recognize and listen to the leadership of the disability community. In fact, they participated in a campaign to discredit these leaders. They repeatedly denied the validity of the vision of community integration for people with developmental disabilities and defended the indefensible—the continued confinement of large numbers of New Jerseyans with developmental disabilities in developmental centers.

Interviewed after the closing, the union leadership continued to hold out institutional care as the appropriate future for people with developmental disabilities. If this immoral and short-sighted position is not altered, they face continuing conflict with the advocacy community and with people with developmental disabilities themselves. We do not believe that conflict is in the best interests of the employees the union represents.

The institutions will close, if only because we will be unable to afford their continued existence. If the unions choose to stand against their closing, they will miss the opportunity to participate in planning the transition. They will miss the chance to make the best possible deal for their constituents. That would be tragic considering the good will that the developmental disabilities community feels toward those who have chosen careers serving people with disabilities.

Structural Problems in Community Services

The Division's current Community Services unit is understaffed and has a series of structural problems. It is the poor stepchild of the system. It is isolated from the institutional system, a fact that hampers good placement practices. It is not equipped with a set of policies that envision who should be placed in the community, where they should be placed and why. It is not ready to accept the challenge implicit in placing the remaining institutional residents.

Internal Conflict at the Nonprofits

The dominant providers of community services are private nonprofit advocacy organizations like the Arc. Many have boards dominated by parents.

This leads to two potential conflicts within the Arc and other nonprofits—both were evident at Johnstone. First, there is a strong and unresolved division between those committed to the future of institutions and those who believe that the future is in community services. Second, Johnstone parents rightly accused these organizations of a conflict of interest. Can the Arc maintain its effectiveness as the major parent group, advocacy organization and service provider, effectively fulfilling all of these roles, when there seems to be an inherent conflict between them?

Why should we address these controversial and thorny issues? It would certainly seem most comfortable to ignore them until they become problems again. The difficulty is that the potential cost is a blunting of the traditional political power of the developmental disabilities community. Without the support of the largely middle-class parents and families who make up these groups, the community may not be able to move any agenda forward.

The IHP

It is obvious, both from available research, and as a result of meetings with Johnstone parents, that there is a continuing problem with the IHP process. It is meant to be a process involving meaningful parent input. Parents do not feel included.

Current IHP policy defines a process of parental involvement. It is obvious that IHP practice has routinely violated the spirit, if not the letter, of this policy.

A FUNDAMENTALLY DIFFERENT WAY . . .



Some have envisioned a transition from an institutional system to a network of community-based group homes. In recent years, however, it has become increasingly clear that many people with devel-

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opmental disabilities can live productive, independent lives in their own homes, with individually designed support systems. It has become clear that many people with developmental disabilities can hold competitive jobs. It has also become clear that group homes are only slightly more cost-effective than institutions—and that they limit the community integration of their residents.

As we close the institutions, we should look beyond the development of group home systems as an alternative. We need to find ways to allow people with developmental disabilities to reach their full potential. In the past, we have tragically undervalued their ability to participate fully in our society.

The closing of institutions offers us a valuable opportunity to reinvest our resources in fundamentally different ways of doing business. This opportunity should be approached seriously. We should not make decisions about the future without thinking deeply about their implications.

Viewed objectively, the current system is extremely unfair. Some people with disabilities are in extremely expensive residential placements. At the same time, 5000 people with developmental disabilities are more or less permanently on waiting lists. Realistically, nothing will be done until their caregivers die or become incapacitated. When they are in clear and present danger, the system will creak into action, and, very likely, place them in a facility.

Since the new approaches are generally more cost-effective, an investment in community support systems for people with disabilities may bring a much higher degree of equity to the system—while allowing people with disabilities to reach their full potentials.

These approaches need further study. New Jersey has very little experience with them. We simply do not know how many of the people currently in the system could live lives of real independence in their own homes. We need to find out.

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