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PUBLIC HEARING

before

ASSEMBLY APPROPRIATIONS COMMITTEE

"Plans to Close Johnstone Training Center"

December 11, 1991
10:20 a.m.
Committee Room 8
Legislative Office Building
Trenton, New Jersey

MEMBERS OF COMMITTEE PRESENT:

Assemblyman John S. Watson, Chairman
Assemblyman Joseph J. Roberts, Jr.
Assemblyman Rodney P. Frelinghuysen
Assemblywoman Clare M. Farragher

ALSO PRESENT:

Michael J. Basarab
Office of Legislative Services
Aide, Assembly Appropriations Committee

New Jersey State Library

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Meeting Recorded and Transcribed by
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TABLE OF CONTENTS

	Page
Alan J. Gibbs Commissioner Department of Human Services	2
Robert B. Nicholas, Ph.D. Director Division of Developmental Disabilities Department of Human Services	9
Gwynn Brown, Ed.D. Assistant Director Residential Services Department of Human Services	9
Catherine Farley Acting Assistant Commissioner Human Resources Department of Human Services	16
Robert Angelo Executive Director Council No. 1 American Federation of State, County, and Municipal Employees	16
Beverly A. Jones Employee Johnstone Training Research Center, and President Local No. 2214 American Federation of State, County, and Municipal Employees	22
Edward Warshawer President Friends of Johnstone	29
Helen I. Steinberg Parent	34
Marshall Bord Assistant Director Association for Advancement of the Mentally Handicapped	36

TABLE OF CONTENTS (continued)

	Page
Marcelle Hoetzel Parent, and Vice-President Friends of Johnstone	41
John Horan Executive Director Mercer Unit Association for Retarded Citizens	44
Donna Archer Parent, and Board Member Friends of Johnstone, and Member Bergen/Passaic Association for Retarded Citizens	48
Eleanor Stone Executive Director State Association of Jewish Federations, and Volunteer State Human Services Advisory Council, and Chairperson Legislative and Policy Committee	50
Sandra Lee Porrata Private Citizen	56
Jose Porrata Private Citizen	58
Deborah M. Spitalnik, Ph.D. Executive Director University Affiliated Program University of Medicine and Dentistry of New Jersey	58
Gerard Ruane Private Citizen	61
Harry Randall Private Citizen	63

TABLE OF CONTENTS (continued)

	Page
Donald L. Klein Executive Vice President Communications Workers of America AFL/CIO Local 1040	69
Adelaide Daskan Private Citizen	71
Diane Jones Private Citizen	72
Steven Agolia Private Citizen	72
Kenny Allen Private Citizen	73
Mary Ann Neder Director Public Relations and Development Association for Retarded Citizens, Raritan Valley	74
Barbara Coppens Member Budget Committee Division of Developmental Disabilities	74
Janet San Clemente Private Citizen	74
Colleen L. Fraser Chairperson State of New Jersey Developmental Disabilities Council	74
Thomas Blatner Representative for People Count Coalition	83
Dr. Kevin Walsh Chairperson American Association on Mental Retardation Mideastern Region	86

TABLE OF CONTENTS (continued)

	Page
Howard Topper Private Citizen	94
Darlene Dennis Private Citizen	96
Patricia Shillingburg Private Citizen	101
John Randolph Private Citizen	105
Kate Blizard Advocate United Cerebral Palsy of New Jersey	107
Anothony Brown Private Citizen	111
Suzette Harmon Private Citizen	113
APPENDIX:	
Statement and attachments submitted by Alan J. Gibbs	1x
Statement submitted by Marshall Bord	35x
Position statement submitted by Frank Nardi President Association for Retarded Citizens	38x
Statement submitted by Sandra Lee Porrata	41x
Statement submitted by Deborah M. Spitalnik, Ph.D.	42x

New Jersey State Library

TABLE OF CONTENTS (continued)

	Page
APPENDIX (continued):	
Letter addressed to Commissioner Alan J. Gibbs Department of Social Services and attached materials submitted by Gerard Ruane	47x
Statement submitted by Harry Randall	57x
Statement submitted by Donald L. Klein	64x
Statement submitted by Colleen L. Fraser	67x
Statement submitted by Denise Walker President New Jersey Day Training Coalition	69x
Statement submitted by Anita M. Kneeley Executive Director United Cerebral Palsy	70x
Statement submitted by Wendy P. Crook Executive Director United Cerebral Palsy of Mercer, Inc.	72x
Letter submitted by Matt Ford Judge Advocate Chapter 32	74x

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tca: 1-20
hmw: 21-40
mjz: 41-55
bgs: 56-81
mjz: 82-116

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NOTICE OF PUBLIC HEARING

The Assembly Appropriations Committee will hold a public hearing on Wednesday, December 11, 1991 beginning at 10:00 a.m. in Committee Room 8 of the Legislative Office Building, 135 W. Hanover Street, Trenton.

The purpose of the public hearing is to take testimony, in accordance with Rule #140 of the General Assembly, regarding the plans to close Johnstone Training Center in Bordentown, Burlington County.

Anyone wishing to testify should contact Michael J. Basarab, Committee Aide, at (609) 984-6799. Those persons presenting written testimony should provide 20 copies to the committee on the day of the hearing.

Issued 11/27/91

ASSEMBLYMAN JOHN S. WATSON, (Chairman): Good morning. We're ready to begin our public hearing. You can see that we don't have a system hooked up so that everyone can hear, so we would like for each and every one that's going to testify here this morning to please speak up so that everyone can have a chance to hear you. Also, we'd like to let you know that in speaking up, even though most of our Committee members are not present this morning, this is going to be recorded. So, it will be a part of the record that we will be able to review and go back to in case we need to get some information for the others.

I would like to read a letter from the Speaker to the Clerk, and it so states: "Gail Marsh Saxer, Clerk, New Jersey General Assembly, State House, Trenton, New Jersey. Dear Ms. Saxer: Pursuant to Rule 140, the Assembly Appropriations Committee is hereby authorized to conduct a public hearing on Wednesday, December 11, 1991 at 10:00 a.m., regarding the proposed plan to close the Edward R. Johnstone Training Center. Thank you for your attention to this matter. Sincerely, Joseph V. Doria, Speaker of the House."

I also want to let you know that we are dealing strictly today with Johnstone. We have over 35 people who are going to testify here today. I would also ask that you try to keep your testimony as brief as possible. I'd like to keep it within five minutes or under, to allow others to be able to testify too. Therefore, I want to thank the members of my Committee: Assemblywoman Clare Farragher, Assemblyman Rodney Frelinghuysen, and Assemblyman Joseph Roberts for being here, and I think others will be coming in.

First on the agenda today is our Commissioner. Commissioner Gibbs, if you would step up please, and also you can identify those from the Department that are with you this morning.

C O M M I S S I O N E R A L A N J. G I B B S: Thank you, Mr. Chairman. I'm delighted to be here this morning. I'm delighted to be back in this room. Fifteen or sixteen years ago, when I was Deputy Commissioner of the Department of, then, Institutions and Agencies we were located in this building, and my office was in the part of the hearing room where you sit. In fact, my desk used to be about where Assemblyman Roberts is sitting.

ASSEMBLYMAN WATSON: Commissioner, you know, for you to remember your different offices here-- I can recall being out of the General Assembly across the street for about four years, and I get turned around everywhere I go. I don't even know where I am anymore. (laughter) But it's a beautiful reconstruction.

COMMISSIONER GIBBS: It is, indeed. It's a much better facility than when I was here last, and the company is far more distinguished.

Mr. Chairman, the budget, as approved by the Governor, for this Fiscal Year, provides for the phaseout of the E. R. Johnstone Training and Research Center beginning July 1. In my testimony this morning I want to bring you up-to-date on where we are with plans to transfer clients, either to more appropriate community settings or to other institutions with certified cottages and higher staffing levels, and our plan to provide employment opportunities to all the staff at Johnstone.

In May of this year we provided you with a plan for closure. Last month, we submitted an amended plan. You might be interested in knowing that we sought comment on this plan at a meeting of parents of Johnstone residents in October. At that meeting -- which we should have had a long time ago -- we explained our plans to close Johnstone. We answered their questions and listened to their concerns. We held this meeting in order to ensure the best and smoothest transition possible. I think our amended plan reflects some of their concerns.

We also shared with the parents, at that time, our projections of the transfer of Johnstone residents through April of 1992. To date, we have placed 51 Johnstone residents. Twenty-one of these residents have been relocated to community placements, and 30 have been relocated to other institutions. We still have, today, about 177 residents at the facility. We expect that by April, we will have completed the placement of 126 clients.

The actual rate of placement depends on two factors: First, the readiness of the receiving facilities to which the residents are assigned; and second, the involvement of the parents.

We make each of these transfers according to an Individual Habilitation Plan or IHP, as we call it. Every placement has been made and will be made in accord with the needs and preference outlined in the IHP, with the parents fully involved.

We are committed, absolutely committed, to ensuring that every Johnstone resident receives a placement that's at least equal, and in most instances better than the current placement at Johnstone. Where this involves a placement in another developmental center, that transfer will be made to an ICF/MR certified living unit with higher staffing levels.

Where a community placement is appropriate, our community liaisons will work with the Johnstone Center staff to develop transitional plans.

I've said it over and over again: Every Johnstone resident will be provided with a placement that will be as good or better than his or her current placement. We've hired an outside firm to access the quality of life of the Johnstone residents before and after they leave the Center.

We won't make any placement that offers anything less. We will correct any situation where we find that our resident has a lesser quality of life in his or her new placement.

I also believe that we have made every effort to accommodate the staff at Johnstone. We have held to our commitment to provide other employment opportunities to staff who will be affected by the closure.

I have directed that vacancies at other Human Services facilities will not be filled until full consideration is given to Johnstone employees. There are, for them, other employment opportunities available in the community service network. We've conducted a survey of Johnstone employees to elicit their preferences for work locations. We've arranged tours of possible work locations and have set up interviews as employees respond and as the vacancies are posted.

We've allowed some special shared job arrangements as the phaseout proceeds to accommodate the operational needs of both the receiving facility and Johnstone. To date, 46 staff have been separated from Johnstone since February. We now have 262 regular employees on the payroll at the facility.

Many of the separations represent early retirement that was selected by employees, but they also include transfers to other facilities operated by the Division of Developmental Disabilities, or Mental Health and Hospitals.

Mr. Chairman, I want to place the closing of Johnstone in a larger context. For most of this century, we've held to a vision of Professor E. R. Johnstone, one of New Jersey's pioneers in providing services to children with developmental disabilities. Johnstone's vision and the vision of other professionals was one of an idyllic institution where children with developmental disabilities lived out their entire lives.

Today, these children and adults have new opportunities. We've changed our vision. We've expanded our programs and services that we offer to them. We take special steps, as we have at Johnstone, to involve and support parents in planning for their loved ones. Today, many of those children and adults can live alongside you or me as neighbors.

We have a different view, a brighter view, that says that no matter how good an institution is, an institution is not a home.

We no longer see most of our clients staying in an institution for their entire life. Yet, even when Johnstone closes, we will be meeting the needs of more than 4000 people in State institutions.

People are no longer waiting to go into institutions; they're waiting to go into community services. Many of the 4000 that I mentioned are waiting to go into community placements.

There's something I also need to make very clear, whether or not we close Johnstone. The money for community placements is very scarce. The money for the Johnstone community placements comes from the Johnstone budget. It doesn't come at the expense of other placements in the community. It is the only way we can assure those residents a shot at a better life in the community.

Closing noncertified beds in Johnstone and other institutions allows us to make additional community placements over and above the beds we close, because the amount we spend on noncertified institutional beds is greater than what we spend on community placement.

Unless and until we make and implement the hard decisions to close an institution like Johnstone, we will never have all of the financial resources we need to meet community placement needs.

Mr. Chairman, as I've said before, at one time the demand was for institutions. Today, the demand is for supported living, independent living, supervised apartments, and skilled development homes.

All of us who make policies or deliver services for those with developmental disabilities face enormous challenges. In meeting those challenges we need to ask ourselves some questions about where we're headed.

Are we headed towards a time when we can provide families with reasonable support and services -- such as respite care and skill development -- to allow a family member to live in the community? Are we headed towards a time when most children and adults with severe disabilities will no longer have to endure institutions, custodial care, and separation from their families and communities?

Are we headed towards a time when we will limit the money we use to support buildings and places and old practices that have remained virtually unchanged in design and intent for more than a century? I think we're headed towards that time. And the credit for that belongs to the families, to the advocates, to legislators, to professionals, and to the public, who fought for the rights of people with disabilities. But most of all, I think the credit belongs to those with severe disabilities, who challenge us to challenge them.

I am confident we will meet their challenge with a full range of support services, with the smallest possible institutions, with certified beds in smaller institutions, with community placements made possible by redirecting funds from substandard cottages, and with respite care and skill development.

With the Governor's support and with your continued help, Mr. Chairman, I am confident that we'll continue to do what's right for the time and for the people we serve. Thank you.

ASSEMBLYMAN WATSON: Thank you, Commissioner. Commissioner, I think the major concern here this morning is the movement of the residents of Johnstone. I know that during the last budget deliberations, when we were able to salvage Johnstone for at least another year, there was a commitment in regards to the overall satisfaction to all, that before there was any movement at all, as our part of the agreement, your office would get back to the Committee and give us your plan on

how you were going to move out residents so that we could all have some knowledge and understanding. And if we didn't have some understanding, we could get some understanding.

That, of course, was brought to my attention when the parents, relatives, and friends of Johnstone clients -- Johnstone residents -- raised the point that they were moving the clients out of the institution without coming back and giving us your plan to do so. I was quite concerned because it was one of our agreements, and one of our commitments. Could you at least explain to us why there was movement before coming back to the Committee and giving us your plan to do so?

COMMISSIONER GIBBS: Mr. Chairman, we did submit a plan in May, and we submitted an amended plan in November. But we did submit a plan in May of this year. While we have made some changes in that plan, and the plan is more descriptive about how parents can be involved in the processes by which we would go through them, the basic part of the plan is unchanged. I believe we did meet our commitment. I believe the amended plan is an improvement on that, and I was happy to submit that. But all of the movement really is predicated on the plan that we filed.

One other change in the plan that I want to note is that when we were testifying before the Committee, at the time that you were deliberating on the budget, we said that of 228 residents, about 84 -- I believe was the number -- would be placed in the community, but our further, individual review of all of the clients at Johnstone has lead us to the conclusion that there are 96 who are suitable for placement in the community. Other than those two changes, we are following the plan as originally proposed in May and amended in November.

ASSEMBLYMAN WATSON: In reviewing your May plan I would say at the least, it was vague. And the plan that was resubmitted in November still is, in some way, vague. We're here now to -- give us just some of what has taken place, how

you arrived at it, and we're going to hear from the parents, I know, of some of those who have been placed already. We want to get your evaluation of what has taken place thus far. Could you just give us some idea of the placements that you've made, and where, and how they have adjusted, or rather, if they have adjusted or not? Then we'll also hear from some of the parents in regards to some of their--

COMMISSIONER GIBBS: I can tell you, again, -- I don't want to be too repetitious -- that all of the transfers are made pursuant to an Individual Habilitation Plan, and have the full involvement of the parents, where the parents wish to be involved and are the guardians. Of the 51 people who have been placed so far, I've indicated before, the community placements were 21. Of those 21, four have gone to group homes, 14 have gone to supervised apartments, and three have gone to skilled development homes. Thirty have gone to other developmental centers -- State-operated developmental centers -- 13 to North Princeton, three to North Jersey, 12 to New Lisbon, one to Woodbine, and one to Ancora.

Of the 51 who have been placed, in terms of family involvement, 19 of those 51 have family who are the guardians of those individuals, 15 are capable themselves -- are their own guardians -- and 15 of them are under the guardianship of the Bureau of Guardianship Services. I'm delighted that some of the focus on this is with the parents, and the involvement of the parents. I know that some of the parents who are here to testify have been through that process and perhaps they will talk about their experiences with it. But to date we have been able to make all of those placements with those parents, and come to agreement on those placements.

ASSEMBLYMAN WATSON: Commissioner, what is the procedure for IHP approval for clients without guardians?

COMMISSIONER GIBBS: I think for the best answer to that I'd like to turn to Bob Nicholas, the Director of the Division, or one of his staff to provide that for you.

R O B E R T B. N I C H O L A S, Ph.D.: Through the Chair, there is a Committee at Johnstone which is the Human Rights Committee, which is involved with the guardianship procedures for each of those individuals and serves as a check against the process. Ultimately, those individuals have been found to be competent, so there are choices of what they want, then they are shown what alternatives are available to them. But what they want is paramount. But there is this Human Rights Committee that has to ensure that the decision-making is appropriate, and that has staff and parents on it as well.

ASSEMBLYMAN WATSON: Could you tell me who is on that Committee?

DR. NICHOLAS: I'd have to ask Dr. Brown, who is our Assistant Director for the residential facilities.

ASSEMBLYMAN WATSON: Good morning.

G W Y N N B R O W N, Ed.D.: Good morning. They are members of the facility that are not directly related to a client, also people from the community, and usually there's a parent involved.

DR. NICHOLAS: We can provide you with a current list of that Committee at Johnstone.

ASSEMBLYMAN WATSON: I would like for you to provide us with the list of the members of that Committee.

COMMISSIONER GIBBS: We will do so.

ASSEMBLYMAN WATSON: We have many more questions. I would like to just first open up the other questioning to Assemblyman Roberts.

ASSEMBLYMAN ROBERTS: Mr. Chairman, thank you very much. Commissioner, good morning.

COMMISSIONER GIBBS: Good morning.

ASSEMBLYMAN ROBERTS: I think, what I would prefer to do is hear from some of the other witnesses. I'm assuming that you'll be here for the balance of the hearing?

COMMISSIONER GIBBS: I will not be able to stay for the full hearing, Assemblyman, but my staff will be here.

ASSEMBLYMAN ROBERTS: Fine. Let me then raise a couple of issues with you. I would be appreciative if you would describe the process that the consultant is following, in terms of evaluating the quality of the placements of those clients that have been removed from Johnstone.

COMMISSIONER GIBBS: They are going to be testifying, I'm told. So, you may want to hear their testimony and then ask them some questions.

ASSEMBLYMAN ROBERTS: I believe the plan indicates that by virtue of using community placement as an alternative for the individuals who are currently in Johnstone, there are assurances that it will have no adverse impact on the waiting lists for community placement?

COMMISSIONER GIBBS: That's right. The funds that support the community placement of the Johnstone residents come from the Johnstone budget. So, if we were keeping Johnstone opened, we would be able to place no more people from the community waiting lists than we're going to place, as we close Johnstone.

ASSEMBLYMAN ROBERTS: You indicated earlier, Commissioner, that those clients that have already been placed in community settings or in institutional placements have occurred with consent of the family or the guardians. If you would, just describe for me the process that goes forward to achieve that goal. What kind of processes and what kind of dialogue is there?

COMMISSIONER GIBBS: Perhaps-- Gwynn, do you want to talk about the IHP meeting process?

DR. BROWN: Each person has an IHP team meeting. The team consists of the various professionals that deal with the individual, the direct care staff or a representative of the direct care staff that works with the individual, as well as

the parent or guardian. At that particular meeting, the goals and objectives for that particular person are discussed. The best placement for that person is discussed. There's an opportunity for a give and take on the part of all individuals.

The staff at Johnstone have worked very hard to do whatever preparation is necessary, including-- If at that particular meeting they're not resolving what they need to resolve, they will go back. They will work through what needs to happen. And what happens at the end is that they come to an agreement as to what's the best possible plan for this individual, and then that is written up and signed by those parties involved.

ASSEMBLYMAN ROBERTS: Just so I'm clear, your representation then is that the parent, or guardian, or family member responsible for making that decision, has approved every placement of any individual who has been moved from Johnstone?

DR. BROWN: To date.

ASSEMBLYMAN ROBERTS: To date.

COMMISSIONER GIBBS: We've made no disputed placements.

ASSEMBLYMAN ROBERTS: I don't raise that to be critical. I know what a difficult process that is in a more conventional decision-making process with respect to placement decisions, so that's good to hear. Just one final question: I, obviously, have a lot more to raise but I'll defer that until we hear from some of the other witnesses. What options have you looked at in terms of uses of the facility, if in fact it's closed?

COMMISSIONER GIBBS: We, as a Department have declared to the Treasury Department that it is surplus to our needs. The Department of Human Services has no other proposed plan for the Johnstone facility. The process the State then follows when a department declares it a surplus is to solicit other departments as to their interests. I think they have done that.

There has been lots of talk about it becoming a correctional facility. And I talked to Commissioner Fauver yesterday, who said that they had been exploring the possibilities of using Johnstone, but that he had not filed a request for that facility since, in his judgment, the facility has a number of problems with it, and he's not sure that it would be suitable for their needs. I don't have any-- I consciously decided to call him about it because I know th that is a matter that has at least been discussed, and the rumors have been flying about it. I don't know whether any other department has filed anything with Treasury. If no State department has a need for it then Treasury takes steps to dispose of it on the open market.

ASSEMBLYMAN ROBERTS: Thank you very much. Those are all of the questions that I have. Mr. Chairman, thank you.

ASSEMBLYMAN WATSON: Thank you, Assemblyman. Next is Assemblyman Frelinghuysen.

ASSEMBLYMAN FRELINGHUYSEN: Thank you, Mr. Chairman. Commissioner, in a private conversation with you last night, I assured you I wouldn't ask you any questions. I have an urge to ask you a question, even though I said I wouldn't, because I'm a little bit confused by something in your testimony. The situation is aggravated somewhat because reporters ask me whether what is occurring here today is in any way going to change the decision that has been made.

Your document for closing Johnstone, "Why and How," of May 1, says -- conclusively -- on page 15, "Johnstone will be closed." Your statement today, pages 7 and 8-- I just want to understand exactly what you mean by-- You said, "There's something I must make very clear. Whether or not we close Johnstone, the money for community placements is scarce." By saying "whether or not we close Johnstone," you're not, in any way, reopening the decision?

COMMISSIONER GIBBS: No. That was a poorly worded sentence. I was conveying there a different meaning, and didn't carefully look at the words. The decision is to close Johnstone.

ASSEMBLYMAN FRELINGHUYSEN: I think that is the basis on which-- Obviously, this is the Chair's call but, certainly, my understanding is that the decision has been made, and we are here to receive testimony from people with that decision having been made. Thank you very much.

COMMISSIONER GIBBS: Yes.

ASSEMBLYMAN FRELINGHUYSEN: Thank you, Mr. Chairman.

ASSEMBLYMAN WATSON: Thank you, Assemblyman. Commissioner, the Superintendent, has he been replaced?

COMMISSIONER GIBBS: Yes, we have a new Superintendent at the institution.

ASSEMBLYMAN WATSON: Could you tell me, was the Superintendent transferred; fired?

COMMISSIONER GIBBS: No. The Superintendent chose early retirement. We did, in fact, make a move to have the Superintendent-- During that period before his election of early retirement, we provided him with an opportunity for another position within the Division. We did so because we are in the process of closing that institution and we need to have leadership at the institution who can carry that out, and do so in a responsible manner.

ASSEMBLYMAN WATSON: Then the Superintendent asked for early retirement?

COMMISSIONER GIBBS: But he was not fired. He was not fired.

ASSEMBLYMAN WATSON: Could you tell me whether he was irresponsible in his position?

COMMISSIONER GIBBS: No. The previous Superintendent-- I said we wanted someone who would carry out

the decision to close that institution. I didn't mean to imply that he was irresponsible. That Superintendent was, very much, opposed to the closure of it.

ASSEMBLYMAN WATSON: Has any other staff member been replaced?

COMMISSIONER GIBBS: Fired?

ASSEMBLYMAN WATSON: In any way: fired, early retirement, transfer.

COMMISSIONER GIBBS: Yes. No. I think what I said in my testimony was, there are 46 fewer people today than what we had in February. I can get a break out. I do have that. A number of people took advantage of the early retirement program. In fact, 25 employees at Johnstone have retired, five have now transferred to other DDD institutions, two have transferred to mental health institutions, one has taken another State job outside of the Department of Human Services. There have been other separations, totaling 10, I believe, but they're really sort of normal separations. People leave jobs all of the time.

There were two layoffs, but they were not related to the closure of Johnstone. We went through a layoff this summer, a general layoff within the whole Department of Human Services, and Johnstone was not immune from that. There were two people there who were laid off. And then there's one person who has been removed, and I'm not sure what the circumstances of that were.

ASSEMBLYMAN WATSON: All right. The five that were transferred, were they transferred by request or transferred by the Department?

COMMISSIONER GIBBS: Well, I guess it would be by mutual agreement. I mean, we are making an effort to find jobs in other institutions and other places in the Department for people at Johnstone. And we make known the opportunities as they arrive and arrange for transfers for people who want to

take advantage of those opportunities. I don't think-- I suppose that some employees would have the view that they're being forced to go someplace else because of the closure. In that sense, it may not have been the most happy circumstance, but these are opportunities that they are taking advantage of.

ASSEMBLYMAN WATSON: Then the five, I would gather that they were called in and probably given other options?

COMMISSIONER GIBBS: I would assume that that's the case. Does anyone want to expand?

ASSEMBLYMAN WATSON: Were any other grievances filed in regard to this?

COMMISSIONER GIBBS: Grievances?

ASSEMBLYMAN WATSON: As far as the transfers or placements?

COMMISSIONER GIBBS: No.

ASSEMBLYMAN WATSON: No. You mentioned 10 others. Could you just give me some idea about the other 10.

COMMISSIONER GIBBS: I don't have the personnel records in front of me. So, I can't, no. The information that I have in front of me has a category of separations for personal reasons or other employment. I take that to mean that, every day, in all of our institutions and offices around the State, people leave for a variety of personal reasons; take other jobs for example, or leave the workplace entirely. That's what I take this to mean. I've heard of no grievances that have come to my level about any of this, and I don't believe that any of the 10 people in this category were separated for any other reason other than they chose separation.

ASSEMBLYMAN WATSON: Commissioner, I was asked to attend a meeting of the Johnstone family members at the old Holiday Inn, now the Days Inn, about six weeks ago -- seven weeks ago -- and we had an open dialogue. Out of the conversations we had, mainly, the people who are employed at Johnstone were saying that they were being muzzled, and if not muzzled, if they continued to talk then they would be harassed.

They were afraid to open up on a free discussion of any kind only because of feelings that they would have some repercussion from the Department as a whole. This did not come from one person. This came from several of the people there, saying that they were afraid to talk. Some of them were even afraid to even feel free to open up with me, and discuss some of the things. I could feel that uneasiness and nervousness in that situation. Could you tell me, is this happening, and if so, could you also tell me whether any of the staff members filed any kind of a grievance in regard to this?

COMMISSIONER GIBBS: Not to my knowledge.

DR. BROWN: No.

ASSEMBLYMAN WATSON: (woman stands up in audience) Yes, would you come forward please? We would like for you to. Your name, please?

ACTING ASSISTANT COMMISSIONER C A T H E R I N E F A R L E Y: My name is Catherine Farley. I am the Assistant Commissioner for Human Resources at the Department. To the best of our knowledge, there have been no grievances filed resulting from the closing of Johnstone. Again, sir, if there are employees who feel that they're being harassed, we have a formal mechanism in place to deal with any type of harassment and I would only plead with those employees to come forward so that we can take care of the situation. I have had, to date, no employees indicating to me any form of harassment.

R O B E R T A N G E L O: (speaking from audience) Mr. Chairman, they wanted to come forward today but were told they could not attend. Okay. Until I threatened them with requesting from you a Legislative subpoena so that they can attend this morning, they were told not to be here. Now, if it was an open and free dialogue, sir, they would have been permitted to attend this very important meeting.

ASSEMBLYMAN WATSON: State your name, sir.

MR. ANGELO: Robert Angelo. I'm the Executive Director of AFSCME. Sorry, for interrupting.

ASSEMBLYMAN WATSON: I must tell you of the tour that I was on at Johnstone. We were touring the facility and in that overall tour we stopped at one of the buildings. Do you remember which building we were in? (negative response) But, anyway, Senator Stockman was beginning to question some of the staff and also some of the residents, and one of the staff members was very outspoken, and I heard with my own ears that, "You'd better be careful how you discuss this Department as an employee." Now, I heard that with my own ears. I'll ask again: Has any kind of directive been given to the employees of Johnstone of how they conduct themselves in free discussion?

ACTING ASSISTANT COMMISSIONER FARLEY: Absolutely not.

ASSEMBLYMAN WATSON: Thank you. Commissioner, we're going to have more questions. Are you going to remain?

COMMISSIONER GIBBS: I didn't plan on doing that. I had planned on -- because I do have other commitments today -- having staff remain to answer any questions that may come up doing the course of the day, so that there would be people here to do that.

ASSEMBLYMAN WATSON: All right, then, I want to thank you for your appearance here this morning, Commissioner. We will be getting back to you, whatever takes place here today, with some recommendations.

COMMISSIONER GIBBS: Thank you, Mr. Chairman.

ASSEMBLYMAN WATSON: Thank you, Commissioner. Next, I'll call up Mr. Angelo.

MR. ANGELO: Thank you, Mr. Chairman. Again, I apologize for interrupting before, but I couldn't let that be said without the correct information coming before the Committee. I've asked Beverely Jones, who is an employee at Johnstone, who is the individual that is here today-- She is the local AFSCME union President at Johnstone, and was on the tour that you spoke of, Mr. Chairman, and is here today only

after I threatened the Superintendent of Johnstone with contacting you about getting a Legislative subpoena so she could be with me today.

To my knowledge, she is the only employee of Johnstone other than perhaps management officials, that was permitted or is here today to shed some light on some of the things that are happening. Before I begin my remarks, I have to say that the question of muzzling employees to come forward to what's happening at Johnstone is something that has been going on since January 28, when the Governor announced that he had plans to close Johnstone.

We've been through many many battles -- many before your Committee -- since that time. There have been other public hearings on the facilities of Johnstone with Mr. Nicholas and other officials of the Department of Human Services. But I want to applaud this Committee because, from the beginning of the budget debate last year, you have shown an extraordinary amount of interest in the issue, not only of Johnstone, but the issue of the care for developmentally disabled citizens in this State.

I know, Mr. Watson, yourself, and Senator Stockman, and others toured the Johnstone facility. I believe Assemblyman Villapiano was on that tour, and at the next meeting of the Committee he came back to report that he saw a feeling of love between the workers and the clients at Johnstone that he didn't see anywhere else. I think almost everyone that has come before you, through these deliberations, has talked about a special relationship that the parents, and the staff, and the clients, and residents who lived at Johnstone had with one another.

And while you heard assertions this morning from the Commissioner, about the plans, I'll take the word of the parents of the kids who are at Johnstone about the programs,

about the treatment that their families received, and their loved ones, and about the benefit they got from the program at Johnstone.

Assemblyman Frelinghuysen has narrowed the issue this morning, that we're not here to talk about whether or not Johnstone will stay open. But, I feel that the issues that we've raised during this debate are legitimate to all of the programs that the State funds. And we're going to talk about Johnstone. We're really talking about the entire system and how the State cares for its residents that are less fortunate.

I have to say that the statements that were made preceding my coming up to the table this morning about staff not being muzzled, about people being allowed to say what's really going on at Johnstone, is absolute perjury. You heard, yourself, someone told that they could not speak about the situation. That goes on in facility after facility, when inspectors, or other surveyors, or legislators like yourselves, come to find out firsthand what's going on. Employees are absolutely told not to speak to those people.

That's why I think hearings like today, and we've had for the past several months, shed light on a lot of things that doesn't normally come forward. And I'm here to say, as a representative of about 10,000 people in that situation, they have absolutely been told, from time to time, not to talk to people that come and visit those programs, and it's certainly happening at Johnstone.

For the assertions to be made by the Commissioner this morning that everybody left of their own accord at Johnstone, after July 1-- I wish we could have some of those individuals here who were sent to the furthest part of the State to work. And believe me, they didn't feel like they had any choice in the matter. But they're probably too afraid to be here this morning, and it's a shame, because we could have really found out what happened.

You know, we hear the Commissioner's statement about the nice plan that's been developed for the employees and the staff at Johnstone. I hearken you back to January 28, when we were told that the reason Johnstone was being closed was strictly an economic decision. I have articles in front of me where Mr. Nicholas and other officials -- up until May when they were required to submit a plan to you-- It was all because of budget considerations that Johnstone was being closed. Then the program switched. And then from May, when the first plan was submitted, it was part of the bigger picture of deinstitutionalize clients from the State system.

So, I don't know what we can believe and what we can't believe. But there's absolute certainty about the fact that after July 1, after the Governor line item vetoed $2 million, that you had included for Johnstone funding for next year, there was a black Friday at Johnstone. Staff were forced out. Some of them took advantage of early retirement because it was to their benefit. Others were sent scattering around the State.

We have employees now at Johnstone that are being told, and you heard this morning -- being given the opportunity to transfer around the system. But when they go to another facility they're made to feel like they're unwelcome. Ms. Jones was on a bus of employees that went to New Lisbon, and were all but told, "Don't come here," by the management staff there. That's not the kind of cooperation that I think you heard this morning from the Commissioner, and that we absolutely feel the employees are entitled to.

Once again, we've had officials from the Department of Human Services testify about programs without one word about the job that the employees at Johnstone have done over the years, and about the love that they have shown for clients. But I think you'll hear that from the parents. I know that you've taken what the parents have said to you over the last several months with a great deal of interest and concern, and I

submit to you the fact that the employees are never mentioned and the job they've done is never mentioned is indicative of the treatment they're receiving from the Department of Human Services.

You mentioned this morning, Mr. Chairman -- and I was happy that you did -- that the Department was required to come forward to this Committee and your counterparts in the Senate, with a plan that you have this morning. Our impression, those of us who worked together last year during the budget debate, was that plan would come to you, there would be a discussion like there is here today, before it would be implemented.

But with the numbers the Commissioner read off, it is obvious. They went ahead and implemented their plan, and now they are going to give you a copy of it, and we think that's wrong. I don't think that's what the veto language said. I interpret that language to mean they were to come to you first. You were the funding mechanism for those programs, and nobody should have been moved until they came before your Committee on a day like today and explained their plans.

You know, there are so many issues that evolve around Johnstone, I don't want to take the entire program this morning. But we've talked on many occasions about if the clients at Johnstone are ready for community placement, that's fantastic. AFSCME, the employees, the parents, everybody would encourage that move into the community. But we feel the program at Johnstone has been so special over the years, isn't that a program worth looking at and saving? Why are we spending millions, and millions, and millions of dollars in out-of-state placements if we have a program that can accommodate some of our citizens who could use that program right here in the State of New Jersey? I only have a partial list of out-of-state contracts that the Department has. Many of them are in Pennsylvania. There are programs listed on here

in New Hampshire, all over the United States. Why can't we look at an idea of bringing some of those clients home to New Jersey as a way back into the community.

The other issue which I have raised with you, Mr. Chairman, on a number of occasions-- Assemblyman Frelinghuysen is also very, very familiar with State-operated group homes. In fact, he was kind enough to visit, last year, in Vineland, the 14 State-operated group homes that now exist, where State employees who have cared for developmentally disabled people for 25 or 30 years have an opportunity to go into the community with residents -- with the clients. At Johnstone, our employees who cared for these kids -- and I think you'll hear from the parents -- the door is shut for them. They don't have the option of moving into the community with the clients. They can move to New Lisbon or North Princeton. Why not give those employees the opportunity to move into the community with the clients? As far as I'm concerned, there is no good answer to that, other than they should be afforded that opportunity. I would ask that, certainly, the Committee consider that as an option in your discussions with the Department.

Mr. Chairman, I would like Beverly Jones, who, as I indicated before, has worked at Johnstone for-- How many years?

B E V E R L Y A. J O N E S: Twelve.

MR. ANGELO: --twelve years, caring for the residents there, to tell you a little bit about what the atmosphere is at Johnstone now, and to talk about, maybe, some of the issues that we have already raised.

ASSEMBLYMAN WATSON: Ms. Jones, you're up.

MS. JONES: Good morning.

ASSEMBLYMAN WATSON: Good morning.

MS. JONES: Mr. Chairman and the Committee: My name is Beverly A. Jones. I am an employee at the Johnstone Training Research Center. I also hold the office of President of Local No. 2214, AFSCME, there. Before I start, and I don't

want to forget just this one little thing: It was brought out when Mr. Gibbs was speaking. You asked a question as to whether or not staff were allowed, or were involved in the IHP meetings. Mr. Gibbs let Mrs. Brown answer the question, and her answer was that there was a team, and she stated different individuals who were involved in that team, including the staff that work directly along with the client. That is wrong. There is a team, but the staff that works directly with the client on a daily basis is not involved. They are not called; they are not asked questions. There is no involvement with the staff and what goes on in the IHP meetings as far as where the student, or where the client will do best -- what institution they will do best at. We are not involved, and I just wanted to make that point very clear before I started with what I had to say.

The next thing is that in February, Dr. Nicholas and Ms. Brown, and a team from the Human Services Commission here in Trenton came into Johnstone, and at that particular time they told us what their plan was; and that was to close Johnstone.

She also -- Mrs. Brown along with Dr. Nicholas -- assured each and every staff member that they would have an opportunity to transfer throughout the State, as long as it was in the Human Services Department. Right now we are in the process of doing that. Although there is a lot of reluctance with all the employees, simply because as Bob stated earlier, as we go out to the institutions on tours -- and they have scheduled for us to take tours of the other institutions -- we're being resented, you know? The staff doesn't want us. The management is giving us the impression that, "We really don't want you Johnstone employees. We don't have any need here for you. We'll take your students, but we don't want you." This is the impression that people are getting, and they are feeling very, very low.

That, coupled with the fact of the transportation problem, a lot of people just can't get to those jobs. Yes, they have assured that everybody will have a job, but I know right offhand that about 20 people will be hitting the unemployment line, simply because they have 20 and 22 years, and they can't get to another place, or they can't see to get to another place, even if it was on a bus line. Those people will not have jobs.

No matter what Commissioner Gibbs says, Dr. Nicholas says, or Dr. Brown, they will not have any jobs. They don't have anyplace to go. So that when I came to them -- my bargaining unit -- about six weeks ago, and told them the information that I had, and that information was that in January, by the end of January -- January 31 -- Gregory Hall will be closed, and that I had to prepare my employees; we have to go. You know, you have to look for another job. At that particular time, that was about the hardest thing that I had to do, because it was almost like I'm telling them that somebody just died. I don't know-- I'm sure that everybody on this Committee has had a relative, a friend, someone who they love, who has passed away, and you've experienced the mourning process. Well, this is what is going on in Johnstone now with the employees. They are mourning, because starting January 31, one of the cottages will be closed. All of the employees at that particular cottage have had to make a decision where they want to go. Most of them have. As a matter of fact, all of them have, with the exception of five. Those five will be coming over into the cottage that I work in, which is Rice Hall, and they are still only guaranteed jobs until April, because that's when Rice Hall is slated to close.

Now, management is not hiring-- Management is hiring temporary people, supposedly to fill the slots of the people who are transferring. These people they are hiring off the street, with no experience with the developmental children who

we work with. The people who are coming in are having a very, very rough time. Not only are they dealing with the stress levels of the clients, they are dealing with the stress levels of the employees, because they are taking their jobs. They are only on a temporary assignment, but nonetheless, they are being replaced, and the stress levels are very, very high. People are walking around in a daze. Students are acting out unbelievably, because they know that they have to leave their home.

One student left yesterday. He is being transferred to Totowa. He can't communicate with anyone. In other words, he can't talk. If you were to meet him, you could not understand him. I can understand him because I've worked with him for 12 years. His food has to be chopped. He just swallows, you know. He has to be dressed. He actually has to be dressed. He cannot put his clothes on. He cannot unzip a zipper or button a button. But yet and still, when he pulled out yesterday, not only did I have tears in my eyes because I worked directly with him, he had tears in his eyes, because he knew he wasn't coming back. We sat him down, and we talked to him; he knew he wasn't coming back.

Three kids left yesterday, and so far three to four kids have left every week. Some don't have families. They are leaving in December. This is Christmas. Johnstone is their home. At least they should have stayed until the first of the year. And we have more kids leaving next week.

These kids are all upset; they're all acting out. And when they are getting to their final destination, the employees of the other institution can't deal with them. We have a student who has been placed at North Princeton Developmental Center and is in physical restraints, off and on, since October -- heavily medicated. So this child doesn't know what is going on, because he's doped up. We have another individual in New Lisbon who is acting out because he wants to come home. He's

just there visiting; he wants to come home. And this particular individual, I've never seen act out.

We went to a Glassboro Christmas party Sunday only to find out that one of the students that we had in one-on-one supervision was allowed to go to an outside party, and everybody at Johnstone knows -- and I don't know whether or not the Commissioner's office knows -- this individual did $4000 worth of damage to my car. But yet and still, he was allowed in the community. This particular individual needed a one-on-one. He was not ready to go out into the community.

Over the holidays -- the Thanksgiving holidays that just passed -- one of the girls from our Valentine Hall who was placed into the community with ARC stabbed a staff. The police were called. The courts are involved. Evidently she wasn't placed right. Something has gone wrong.

I'm not saying that they shouldn't go if this is what the budget is calling for, but the people-- Somebody is not doing their job. Somebody is not doing their job. (Name deleted) stabbed a staff person at a supervised apartment. (Name deleted) is in physical restraints, off and on, since October. You have a (name deleted) who has a law suit.

ASSEMBLYMAN WATSON: Pardon me, Ms. Jones.

MS. JONES: Yes.

ASSEMBLYMAN WATSON: I'd like for you to make your point, but if you would refrain from naming names at this point. We're here to hear -- names of the clients-- We're here to find out some of the kinds of things that you're interested in and that we're interested in. We would like you to just refrain from naming the names of the clients.

MS. JONES: Yes, Mr. Chairman. I'm sorry. My main interest is that each individual get--

ASSEMBLYMAN WATSON: At this time I would just like to make one more request that those names would be restricted from the transcript. Continue.

MS. JONES: Mr. Chairman, my main issue is that each of the clients who are at Johnstone get a fair, individualized, teamwork done on them before they are transferred to another institution; that wherever they go, yes, they get the same kind of treatment that they have gotten at Johnstone. So far they haven't.

My other interest is that all of the employees who have worked so many years, and gave such dedication to their jobs and to the individuals that they have taken care of, be compensated with another job within the State Department of Human Services that is equivalent to the one that they are doing now.

That's basically it.

ASSEMBLYMAN WATSON: Thank you for your testimony. We would just like to ask a couple of questions, Ms. Jones. Gregory Hall--

MS. JONES: Yes.

ASSEMBLYMAN WATSON: --the first that will be closed down. What is the kind of residents that we have there, and why is that being chosen as the first to close?

MS. JONES: The type of residents who are housed in Gregory Hall are all men over the age of 21. They are more aggressive type individuals. Gregory Hall was slated to be first to close because it was in the poorest condition. I understand that there was a lot of extensive repair work that had to be done, that the State was not willing to pay for.

ASSEMBLYMAN WATSON: How many residents are in Gregory Hall?

MS. JONES: I don't work in Gregory Hall, but I would assume at least, when they are operating at full capacity, about 60, maybe a little more.

ASSEMBLYMAN WATSON: About 60. Could anyone, or could you tell me, where are they being placed?

MS. JONES: Some have gone to the community, North Princeton, New Lisbon, and I think a few are going to Totowa.

ASSEMBLYMAN WATSON: All right. You say some are going back into the community now, and you say most of these are 21 or over? You have about 60? Are these people that you feel are going into the community, are they ready to go into the community? Are they kind of passive or-- Could you give me some kind of feeling of just what kind of residents we are dealing with?

MS. JONES: Some of the residents in Gregory Hall-- First of all, I don't work directly with those residents, okay? But from what I have observed, and I have talked with the other employees, yes, some of them are ready to go to the community, but very few. If you come into Johnstone and if you sit down and listen to their IHPs as the meeting is going on, from that, yes, they are ready to go to the community, because of the fact that they have 24-hour supervision, so that if they don't get up at a certain time, there is somebody there to do it. If they have an opportunity to cook in a kitchen, and the cooking time period is up, if they don't turn it off, or turn the meat over, there is somebody there to do it. If they go out into the community, there isn't a person who is there with them on a constant basis. There may be a supervisor there lodged in another apartment, but not in the particular apartment that they are in. So, no, a lot of them aren't ready to go to the community.

ASSEMBLYMAN WATSON: Thank you. Any other member? (no response)

Do you have any last statement to make, Mr. Angelo?

MR. ANGELO: No. Again, I just really want to indicate that the Chairman's interest in this issue has been recognized by all of the employees, and I think, the parents, and we appreciate it very much.

ASSEMBLYMAN WATSON: Thank you.

Well, I want to thank Mr. Angelo and Ms. Jones for testifying here this morning.

Next is Mr. Warshawer.

E D W A R D W A R S H A W E R: Thank you, Mr. Chairman, and members of the Assembly Appropriations Committee. I want to thank you for giving me this opportunity to speak for the Friends of Johnstone. I am speaking on behalf of the Friends of Johnstone as the President.

It has been 10 months since the surprise announced closing of the Johnstone Training and Research Center. During the past 10 months, the Friends of Johnstone has been fighting to keep this facility open. The success and track record of Johnstone speaks for itself.

In a community atmosphere, Johnstone provides extensive programs and services to meet the requirements of the young and special needs clients that are not available in most of the other developmental centers. The continued success and progress that has been made by the residents is the primary concern of the families and friends, if Johnstone were to close. The transfer of any resident is very delicate and since there were high failure rates prior to placements at Johnstone, regression must be carefully avoided.

We, at Johnstone, have heard the chant for deinstitutionalization. We are not opposed to it, by any means. Before we accept such a move we must be totally confident that there are enough programs, services, and equal or better living facilities available and ready in the community. We must have some guarantee that in cases of failure, there remains an appropriate placement such as Johnstone.

We do not accept that closing Johnstone will be the solution to the funding problems of the community. The truth of the matter is that years of underfunding for the developmentally disabled in the State of New Jersey is the real problem, and that is why there are 10 developmental centers. The shifting of 150 persons out of Johnstone to the other

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developmental centers does nothing to solve this problem. If the State had really taken the lead in community programs and services for the developmentally disabled, then it could have been proper to phase out or close more developmental centers.

This is not the case in New Jersey. In fact, for a State that ranks close to the top in per capita income, we rank in the bottom third in nearly every spending category for persons with developmental disabilities as compared to the rest of the nation. These shameful statistics must be improved before emptying out our institutions. The scarcity of group homes, reductions in programs, the difficulty in getting enough doctors, dentists, and specialists in treating the mentally retarded will not be solved if Johnstone closes. The fact is that we must provide more funding and services for the retarded in the community in order to be able to better serve the population of the developmental centers.

A plan was never initially presented or discussed with the parents and Friends of Johnstone, and for that matter, with the head of Johnstone itself, the Superintendent. In the budget, the wording specifically stated that a plan must be developed and reported to the Legislature. The Friends of Johnstone had also requested, at the very start, for an actual cost analysis and impact statement.

Finally a plan was presented to the Legislature and the parents in October. The plan mainly presented transfer data on how many clients are to be moved, when and where. No changes or additions were requested from the parents for inclusion to the plan. In the case for deinstitutionalization, the plan only places one-third of the residents in the community, while the other two-thirds are to be sent back to the larger institutions from where many of them came. Who knows for how long? Maybe a lifetime. This would be a very sad example for the advocates of deinstitutionalization.

The plan, although it may have the best intentions to place residents in equal or better settings, actually lacks detail on how this will be done. It does not spell out programs needed, services needed, fallback plans, social programs, and so forth. The plan should show the implementation of new programs and expansion of services guaranteeing to meet the demand of the Johnstone population. Dollars should be appropriated to maintain new needs and must be made in addition to the requirements for those still waiting placements and programs.

The intentions of the Department of Human Services may have been good for closing an institution, but it is the consensus of the Friends of Johnstone that the selection of the smallest, most successful training center was not the proper place to start. Johnstone should be continued as a training center for the special needs, mentally retarded, developmentally disabled persons; for those that do not belong in an institution, yet are not ready and need more training before being placed into the community. Johnstone should be considered for short-term residency, and those that have been sent out-of-state at a higher cost, should be returned to Johnstone for care and training. In this way, Johnstone can be used to prepare persons for community placements and reduce the costs of expensive out-of-state residency.

The decision by this administration to close Johnstone was made exactly as that of the unfavorable State tax package. It was made with good intentions, but was made without planning or analyzing, and in a very hasty and dictator-like fashion, with no public input or debate. This administration, making similar mistakes, did not take into consideration the impact on residents, parents, families, and friends. It did not listen to input from our legislators. Governor Florio line vetoed and removed $2 million from the Johnstone Training Center in the budget. Why wasn't this money added for programs so badly

needed in the community if reasons were for deinstitutionalization? If this facility will be used for the Corrections Department as rumored, costs for renovations would far exceed those needed for Johnstone. Is this a budget savings? This administration accepted a plan that had no detailed information, no cost analysis, and no impact statements from the providers in the community and other developmental centers who will be responsible for the equal or better placements and care of the Johnstone residents. Is this how this administration operates?

It is for these reasons that the Friends of Johnstone is against the premature, but good-intended motives to close Johnstone.

Thank you, Mr. Chairman, and members of the Assembly Appropriation Committee.

ASSEMBLYMAN WATSON: Thank you, Mr. Warshawer. Now, would you, just for the record, state your name and the office that you hold?

MR. WARSHAWER: My name is Edward Warshawer. I am President of the Friends of Johnstone, a parents' advocate group at Johnstone Training Center.

ASSEMBLYMAN WATSON: I have a couple of questions that I want to ask you. In your October meeting, the Friends of Johnstone was invited by the Department on a meeting on the plan that was being presented. Is that true?

MR. WARSHAWER: Yes, that's true, Mr. Chairman.

ASSEMBLYMAN WATSON: Could you tell me about how many attended that meeting?

MR. WARSHAWER: We had a total of I'd say about 30 to 40 parents, and I'd say pretty close to the same representation between DDD, the Council, and other advocate groups. I'd say about a total of 60 to 70 people were there.

ASSEMBLYMAN WATSON: And then the plan was laid out?

MR. WARSHAWER: Yes, the plan was presented. In my opinion, the plan was very similar to previous information that we received back in April or May. As I said, Mr. Chairman, the intentions appear to be very sincere, but there was really no up-front work on how these accomplishments would take place. It was more or less -- excuse the expression-- It appeared to be like lip service: just very nice, kind words that would have been hoped to pacify the parents. Unfortunately, there were a number of parents that did leave abruptly, and were very dissatisfied with what they heard, because the plan, again, did not really give much of a choice to anyone. I guess some parents may have thought that there would be more of a possibility to change certain things.

ASSEMBLYMAN WATSON: Well, that's my next question. What input did you, or others who were present, have in discussing the plan? Did they ask for any recommendations after?

MR. WARSHAWER: Well, I could say yes and no. They asked for questions, okay? And the questions were answered to the best of the ability of those who were asked the questions. But there was really no sound foundation of how any changes or input would really get into that plan. There was really-- I don't recall anything or any statements made that said, "Yeah, we will work this into the plan," or "We will change the plan," or "We will consider it."

ASSEMBLYMAN WATSON: So there was no room for compromise.

MR. WARSHAWER: There was no real compromise. It was just a matter of answering the questions as things stand.

ASSEMBLYMAN WATSON: Any other members? I see no other member prepared to question Mr. Warshawer. Thank you for your appearance here this morning.

MR. WARSHAWER: Thank you, Mr. Chairman.

ASSEMBLYMAN WATSON: Next is Ms. Helen Steinberg. Good morning. Would you state your name, and the office you hold, and who you represent.

H E L E N I. S T E I N B E R G: Good morning. My name is Helen Steinberg, and this morning I am here just to represent myself as a parent of a severely developmentally disabled child. I live in Plainsboro, New Jersey. I want to thank you, Assemblyman Watson, and members of the Assembly Appropriations Committee, for listening to my testimony today.

I come before you to explain my support for the closing of the Johnstone Developmental Center. In order to do this, I feel that I must give you some background about my own personal experience. This will better identify my response as one which has been given a great amount of thought.

My 11-year-old son, Jason, is severely developmentally disabled. He needs total assistance to walk, to dress, to eat, and to do simple tasks. He is nonverbal and is still in diapers. He has a severe and uncontrollable seizure disorder. Jason has lived home with his family for all of these 11 years. However, this is not how I have always envisioned life.

There have been times when he was two and three years old, and on and off since then, when my husband and I have felt that Jason would need complete residential care at some point in the future. We thought that it would become too difficult for us to continue to care for his daily needs as he got older and bigger in size. We were told when Jason was two years old that we could never expect him to even reach a two-year level of abilities and understanding. This seemed devastating. We were not young parents, and I already had had some problems related to arthritis. When Jason was eight years old, I injured a nerve or two in my neck causing horrible pain from my neck down to my fingers of my right arm. Total residential care seemed to be where our future was leading.

In order to survive immediately, I had to engage the use of home health aides. At first I needed them whenever Jason was home and awake, since I could barely feed myself, much less take care of his needs. Little by little, I was able to pull back from my dependency on outside assistance, until reaching the level at which I now maintain a home health aide three mornings a week for one-and-a-half hours per morning. I have also opened my home to a woman from China who gives me 30 to 40 hours per month of respite in place of rent.

Now I know that I can keep Jason home, where he belongs. I can survive as long as I have enough assistance. Jason is happy and content with his life. Just to see the expression on his face when he comes in the house after school would convince anyone that he knows that he is home and that he is truly happy to be there. He also gets excited at bedtime when he goes into his bedroom and sees his familiar surroundings. Jason takes part in family gatherings. He enjoys his time at school, both Mercer Day Training Center, and his one art class per week at West Windsor-Plainsboro with typical fourth graders. In general, Jason truly enjoys taking part in his community as any other citizen.

My vision now for his future is that he should remain in the home that he has grown used to and enjoys. With proper supports he can stay there. As it becomes beyond my capabilities to care for him at all, I hope to be able to find others to take my place. He could easily have housemates who on alternating schedules could manage to meet his needs.

At present, my insurance helps with the cost of the home health aide since the State was unable to supply me with the help I needed. Even respite has been handled on my own since the State and other agencies were not able to meet my schedule needs and the consistency upon which I am dependent.

What all of this has been leading up to, is that I do not feel that we should spend money to repair any developmental

centers. The people who are presently there may not have had the day programs such as my son has, and may not have had respite to help their families. However, day programs and good family support are the better solutions for these people. In the cases where the family could not possibly keep their loved one at home, there should be other in community solutions for them. In community means smaller rather than larger facilities, and means jobs or some kind of program of activities and/or therapies administered within the community. People with developmental disabilities need to interact with their neighbors and families, and to develop friendships.

More severely disabled, medically frail individuals can also be handled in smaller settings. Nobody needs a strictly hospital type setting. Medical needs can be met while still providing an atmosphere of warmth and home life.

Those of us who have been keeping our children home want something better than what has been offered in the past. Therefore, I, and I am certain other parents such as myself, would rather see in community placements and strong, consumer driven family support programs for those living within their own homes. In the long run, I truly believe it will be cheaper for the State and will serve many more individuals with developmental disabilities. With the growing number of families requesting family support, it would be wise for our State to do all in its power to meet these needs and thereby decrease the demand for residential placement.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Ms. Steinberg. Does any member of the Committee-- I see no member has any questions, so thank you for your testimony this morning.

Next is Marshall Bord. Good morning.

M A R S H A L L B O R D: Good morning, thank you.

ASSEMBLYMAN WATSON: State your name.

MR. BORD: My name is Marshall Bord. I'm an Assistant Director of the Association for the Advancement of the Mentally Handicapped, a private, nonprofit agency that directly serves people coming out of the developmental centers, among others. In fact, with me today are several people who were in developmental centers and some other people who could have been in developmental centers, unless they had received some real focused, helpful supports throughout their lives, and with those supports have gone one hell of a long way, whether it be (names deleted), and they are all available to talk with you or meet with you at your request, and let them tell you their own stories. I don't intend to do that here.

We welcome the opportunity. If you want to see where people from developmental centers go, or can go -- and hopefully will be going -- I would welcome you to Union County, and to Elizabeth, and to Hillside, and to Linden, and most recently to Plainfield and to Roselle, to see the physical and not homelike, but homes, where these people now live and the level of care that they get and the level of supports that they get and the progress that they make toward leading a more and more normal life. Everybody has that right: To lead as normal a life as their God-given resources enable them to live.

I turned over to you some testimony written by a sister of a -- I was going to say a young man, but that's not fair to him; he's 53 years old. From my perspective, that's still young. I will not read it to you. That was initially my intent, but you can all do a whole lot better reading it yourself.

Simply to sum it up: A young man with Downs Syndrome, at age 17 was placed by the family into a private institution -- and I underline the word institution. He was there for 36 years. Things didn't go as well as they had in the past there. He was very unhappy. The institution decided that it

was his fault. Therefore, if he was unhappy, they would medicate him. Nothing that they were doing could possibly be at fault.

The sister, who was the legal guardian, opted to look for alternatives. We were among those that she talked to. In October, (name deleted) left the private institution and moved into his own apartment in Hillside, and spent the next month, mostly, awake, singing "Born Free." I'm not offering that in any facetious sense. I mean, literally. I met him. I see him on a weekly basis, or more, and even when the euphoria and when the honeymoon period dies down, which may last another month or so, he and his family both, feel -- sense, know -- that he now has a chance to do things that he never did before: to control his own life, to hang up the pictures in his room that he wants to, to have some input into what he eats, and maybe even have some input as to when he eats, and to be trained for competitive employment -- and not trained for 30 years, and then retire without ever having gotten there -- but into a real competitive job. I think some of the people here can share the same experience.

(Name deleted), for example, would now be declared, under the 1985 switch, developmentally disabled. In another period of time she might well have been placed into an institution. And what a loss, not only to her, but to the rest of the world. (Name deleted) comes back to us from a little visit to Washington last month where she was New Jersey's recipient of the President's Victory Award, for the individual in New Jersey who in 1991 was the most laudatory, most successful, in overcoming monumentally severe -- in this case -- birth handicaps, or disabilities. (Name deleted), too, would be more than willing to share a few words with you.

This whole issue hits me so hard, and I had to think about why I am so emotionally charged about this whole thing called deinstitutionalization. Obviously, my job is related to

it, and it's a job that I chose to take. I've testified before this Committee any number of times over the last more than a half-a-dozen years, and yet yesterday the adrenaline was coursing through my body, and I had to, for the first time in my life, try to figure out what was going on inside of me. I would like, with your forbearance, to share it with you. Perhaps I should have done this 40 years ago, but I didn't.

What is my identification with this whole issue of deinstitutionalization? Why do I feel so damned strongly about it, and why is it that I think people should have the right to impact on their own lives, and to live as normally as possible? And living with 60, or 80, or 100, or 120 other people is not the way anybody up in front of this room lives. It's not the way I live, and it isn't normal. It isn't normal. I think we continually confuse the level of services needed with an institution; the more services needed, the bigger the institution. But as the speaker before me said, that's not necessarily true. It's only true if we make it so, so that whatever services are needed can be provided in a more humane, more beneficial, more home-like experience, or more home experience, literally, so that I very much share the perspective.

But for myself -- and I think I am unconsciously veering off the topic. I was born in 1934. By 1936, my parents were taking me to foot doctors because I kept falling. They finally figured out that it wasn't my feet, but that I was born with a damaged optic nerve, that from birth has made me legally blind. At age five or six, my parents were confronted with a decision -- and I'm doing this now from hindsight, and I'm doing it from hindsight that I really began to dig at over the last week, and came to this "monumental" insight last night. At age five or six they had to have been confronted with the problem, "What do I do with this kid who is legally blind? Do we mainstream him, or do we put him into a private

facility, or into a State-run institution, as the case may be?" where I would get very good care, where I would not be at risk of running into an automobile, where my individual needs and problems would be dealt with professionally. And the decision was made to mainstream me. So I went to public schools in Brooklyn, and about age eight or nine, I found my sister's old roller skates -- the kind that you clamp onto your shoes -- clamped them onto my shoes, went outside and started to roller skate up and down the streets of Brooklyn. I rather suspect that both of my parents had any number of angina attacks watching me ride up and down the streets, not really knowing whether or not I could see the vehicles coming toward me and coming from behind me. But still the decision was made: "Let's risk it. Let him try; let him try; let him try."

And they let me try, and they helped me where they had to, and I've gotten a lot of help throughout my life. And I am literally sitting here before you, begging, imploring, demanding, that the people at Johnstone, and the other institutions around the State of New Jersey, get the same damned opportunity that I had to lead as normal a life as possible.

Are there problems? Are there periods of discomfort? Are there failures? Of course. But the real failure -- the real failure, not to do it, is not to try, not to let people maximize and build on themselves and learn to be their own person. That's the failure.

And with that I would simply reiterate my invitation to all and any of you to simply give me a call -- the number is on the front of the testimony, on the lead sheet. I would be more than glad to show you what a supervised apartment can, and does, look like; to meet the staff who work 24-hours a day with the people coming out of Johnstone, or Woodbine, or Totowa, or wherever: with the families who remain involved, and with the individuals who are coming out -- not children, as some of the

previous speakers refer to them -- not children, not kids, but adults. Adults who demand our respect and should not be treated as children, because the less we expect from them, the less we are going to get; and the more we expect, the more we are going to get.

Come see them, please, I beg you. Some of them are here now, they would be more than glad to chit-chat with you at your convenience. I think perhaps I should request forgiveness for the urgency, maybe anger, fervor I hear in my own voice, but obviously this strikes a strong, strong personal cord that goes well beyond my professional obligations.

Thank you for the chance to emote, cathart, and share my feelings with you.

ASSEMBLYMAN WATSON: Thank you, Mr. Board, for your testimony here this morning.

Next will be Marcelle Hoetzel. Good morning.

M A R C E L L E H O E T Z E L: Good morning, Mr. Chairman. Thank you so much for all your kindnesses, and to the other members of the Committee. I am Marcelle Hoetzel. I am a parent of a son at Johnstone. I am also the Vice President of the Friends of Johnstone.

About a year ago today, parents and families were preparing for the holidays, completely unaware of what would be happening to their children at Johnstone just a few weeks later. We were content with the knowledge that our children were safe, well cared for, and had the assurance that their future was bright and we did not have to worry about them at long last. We were certain that when our children were finally ready and prepared to go into the community, it would be done properly, guided by the Johnstone officials and staff that cared about our children's well-being.

The devastation that has taken place since the end of January 1991, has taught us some very painful lessons and that we must always remain vigilant in our children's lives.

We approached the legislators in the State with our desperate pleas. A few of you really cared, but sadly our pleas and cries fell mostly on ears that would not hear.

We were naive enough to believe that the State ARC and all the advocacy groups that built community homes cared about all the handicapped and developmentally disabled, and that they would surely come forward to help the Johnstone children and ensure their safety and well-being. It was never anticipated that they would turn their backs on our children for their own political gain, hoping to add funds to their own special interest group, sacrificing the well-being of the Johnstone children.

We heard statements from ARC, DDD, and the developmental councils that our children were languishing in the Johnstone rat hole. "Let's help them move into the community, give them less restrictive quality lives." The public bought this. It sounded good, but this is not what has been happening to our children.

Many of our Johnstone children who previously walked the grounds freely and safely have been moved to much larger institutions and are now in lock-up facilities. They are mixed in with lower functioning and, in some cases, more aggressive clients, placing them at risk of being hurt.

Since the November elections, there has been a mass move at Johnstone to dump these clients as quickly as possible, to make the saving of Johnstone impossible when the new Legislature takes office. Proper IHPs are questionable, sometimes done as someone is heading out the door. Christmas, for these children, doesn't matter. They are being moved right before the holidays. The school is expected to be closed in January, and the kids will be bused to New Lisbon.

All the clients are expected to be in the other developmental centers by April of 1992, leaving a handful to be placed in the community. I am told they are not building group

homes in Bergen County. There are many Johnstone families that reside in Bergen County, and this is where their children should be moved to be close to their families' support system.

New Jersey argues that we are behind other states by having the most developmental centers. Perhaps that is true, but most states build quality group homes before they close the institutions. The way New Jersey is going about this, the developmentally disabled are in very real jeopardy of finding themselves among the homeless, along with those thrown out of mental hospitals. We must have a mandate to oversee the well-being of these vulnerable citizens placed in the community. They must be checked on frequently to make sure their living conditions, health, and needs are being met. They must not be abandoned by an uncaring bureaucratic system.

Legislation must be passed to ensure the safety of those remaining at Johnstone during the phaseout. They must not bring in inmates from Corrections and endanger the Johnstone population. Proper care and staff must remain in place to protect these children. They have already begun to mix the living arrangements at Johnstone to cut back the need for staff. They are mixing the aggressive and more street-wise with the nonverbal and quieter student, putting them at the risk of being hurt. They should not be sacrificing their safety for the dollar.

With the more than 4000 on waiting lists and all the desperate cases in inappropriate placements, the closing of Johnstone is a tragedy. There are very few group homes being developed. They say they will save money by closing Johnstone, but the money will be there to renovate it for Corrections and drug offenders. Money is very limited for the developmentally disabled, but I will never understand why, during such hard times as we have witnessed in 1991, so many millions of dollars keep pouring into the State House renovations. I'm sure the stained glass skylights and chandeliers, as well as all the

marble and brass, are magnificent. Where are the priorities? Something is terribly wrong in this State. Money that was earmarked for Johnstone's maintenance was diverted elsewhere. Why wasn't some of this elaborate frill money sent to help these children desperately in need of your help?

Please, we beg you, hear us. We are speaking for those unable to speak for themselves. Thank you.

ASSEMBLYMAN WATSON: Thank you for your appearance. Does any member of the Committee have a question? (no response) Hearing none, thank you for appearing this morning.

Next will be Mr. John Horan. Good morning, Mr. Horan.

J O H N H O R A N: Good morning.

ASSEMBLYMAN WATSON: Would you please state your name and your office, or who you represent?

MR. HORAN: I am John Horan. I am the Executive Director of the Mercer Unit, Association for Retarded Citizens.

ASSEMBLYMAN WATSON: Thank you. You may continue.

MR. HORAN: Mr. Chairman, I appear here today as the Executive Director of an Association that provides a rather broad spectrum of community services, to give you and the Committee some insight as to our success with people who enter and leave those services.

I would like to depart from my written remarks just to say that I, myself, am a person who was formerly institutionalized. This was at a very early age, between seven and thirteen years. I was in the Widener Memorial School for Crippled Children. You will notice the descriptors of the institution, but thankfully that kind of thing has changed. We don't use "crippled" too much anymore.

However, while my experience was not totally negative, I have never forgotten the isolation, being in a ward with 60 or 70 other people, having to eat at particular times, having to recreate with everyone else. Those are the kinds of institutional things that remain with you, and do not go away.

Mercer ARC has, for many years, had Johnstone residents who were successful extended employees of the Association's Occupational Training Center while they lived at Johnstone. In addition, over the years, Mercer ARC has assimilated persons who were discharged from Johnstone into its community residential living programs.

I would like to take this opportunity to describe the progress of some of the former residents of Johnstone, who are today living and working successfully in the community. One adult reentered the community in 1980 and resided in a Mercer ARC group home for six years. He then progressed to supervised apartment living, where he now maintains his own apartment. He has been competitively employed since 1986.

Another entered a supervised apartment setting in 1983. He moved to supportive living, which is a more independent situation, in 1985. He has worked competitively since 1987, and is presently living with a friend in a rent-to-own condominium.

Another entered ARC programs in 1982. Becoming a resident of a group home, he moved to a supervised apartment in 1987, where he is at present. He is employed in ARC mobile supportive employment, and is current President of the Mercer self-advocacy group called HOPE.

Four other former Johnstone residents were referred to Mercer ARC's residential programs in July of this year. The four gentlemen are living at the White Horse Gardens Apartments, a supervised apartment living situation.

By the way, the comment was made in earlier testimony that there is no staff to give instruction or to be there when the residents need them during the day or the night. I can say for our Association that this is not so. We do have staff round the clock. We do have interested staff. While they do not intrude on the living arrangements of the persons involved, they do, indeed, make sure that they are there when called and needed.

Of the four former Johnstone residents living at the White Horse Gardens Apartments, each has made a good adjustment to community living. For example, one is employed at a thrift store. Since he is only 18, he also has plans to return to school in the community. Another is employed at the Burlington County OTC, where he has been working for the past six years, even while a resident of Johnstone. He is very serious about developing his skills for independent living, so he may be able to move to a situation which has even less staff involvement.

Another has shown great progress since his initial entry into his apartment. He is presently employed at Mercer ARC, where in a short time it is hoped he will move to a job in the community.

The last person I want to comment on has made an excellent adjustment to community living. He is 95% independent at this time in his budgeting and banking skills and in caring for his residence. He is assertive; he is articulate, two of the qualities which have earned him a seat on the Association's Board of Directors as its consumer representative.

Recently, I had the pleasure of appearing with this person on New Jersey Network TV, where we were interviewed concerning the difficulties which are faced by developmentally disabled persons living and working in the community. The adult described his employment with Petro Truck Stop in Bordentown and his aspirations for the future. When asked what he liked most about being out in the community, he cited the freedom of choice which is available in his present situation, and the fact that he, individually, can make of his future what he wants it to be.

Mr. Chairman, the experience of our Association with former residents of Johnstone and with President referrals, is that given the opportunity and the necessary support, they can, and will indeed, become contributing members of their communities.

I thank you for this opportunity.

ASSEMBLYMAN WATSON: Thank you, Mr. Horan. Does any member wish to question Mr. Horan? (no response) Mr. Horan, I know I received a statement -- a position statement -- issued by Mr. Frank Nardi of the Association for Retarded Citizens. I just want to read, for the record, a paragraph of what Mr. Nardi sent to this Committee. It states:

"The Association for Retarded Citizens of New Jersey hopes that it is the intent of this Committee to ensure that the quality of life of individuals with mental retardation and other developmental disabilities is preserved. And, we hope that the impetus for this meeting was generated by concern for the welfare of the residents of the Johnstone Research and Training Developmental Center, and not the displacement of unionized staff working at this facility."

I want to note for the record, I think this paragraph is a little insulting. I called this meeting for the citizens of this State, especially those sitting in this room today. And this is what we are hearing from the parents and the friends of the Johnstone people, and from the State. This was called for notification of how we are going to conduct ourselves with regard to the total situation of Johnstone. I just wanted to say that for the record.

MR. HORAN: Mr. Chairman, I understand, and I appreciate your concern with the statement. I wish to clarify my own unit's position within the State strata. Mr. Nardi represents the State Association. There are 20 autonomous units to that State Association. We do not necessarily subscribe to every statement made by the State President. I certainly agree if you are concerned.

ASSEMBLYMAN WATSON: I think Assemblyman Frelinghuysen has something to say.

ASSEMBLYMAN FRELINGHUYSEN: Let me echo the Chair's sentiments. I think that was totally uncalled for.

MR. HORAN: I agree.

ASSEMBLYMAN WATSON: Thank you, Assemblyman, and thank you for your testimony, Mr. Horan.

Next will be Donna Archer. Ms. Archer?

D O N N A A R C H E R: Good morning. I am Donna Archer. My son is a resident at Johnstone. I am on the Board for Friends of Johnstone, and I am also a member of the Bergen/Passaic ARC, which also supports Friends of Johnstone.

Some of the issues that were discussed this morning-- I don't have a written paper for you because I didn't know until last night whether I would be here or not. I felt that today we were here to voice our concerns about the closing of Johnstone. One of my large concerns is that the staff there is being intimidated. I have spoken to several of the staff. One of them actually cried the day I went there for my son's IHP, because of the way they are being treated and her concerns on how this would affect my son. If there is stress and tension there -- and these kids need really delicate care -- how is this going to affect them?

My son was home for a visit in October, and he was extremely agitated over the closing, people leaving, and what is going on. I hadn't spoken to the new Superintendent, and I called that Monday just to tell her hello, let her know that I was looking forward to working with her, and that I had some concerns. The first one I had was, there was a rumor going around that inmates would be occupying Gregory Hall. She told me that was absurd, and she couldn't believe that I would even call with something so ridiculous. The other concern I had was, was there any staff there to help to counsel the kids because of these concerns about leaving? She told me that my son had a social worker and that that was what she was paid for.

I felt that if they really want to work with the parents, there should be some sensitivity. These are our children, and they are looking at it as a job. To correct the

Commissioner the other day when he spoke about the meeting we had in October, he talked about this meeting like it was a productive meeting. It was not a productive meeting. It ended in a fiasco. People walked out. The things they promised that night-- The most important thing I voiced was that people would be moving at Christmas. Christmas is a very difficult time for these residents, because some of them do not have families. Even the ones which do have families are concerned with, will somebody pick them up? Will they get home? They are still moving these people. You and I would not choose to move or to make any plans around the holidays. Why can't they do the same for these residents?

The other concern I had was, this stress has been going on since the time that the last Superintendent left. Now, he claims that he resigned. He resigned, but there were restrictions that he could not go on the property. He could not say good-bye to the residents. He could not socialize with any of the workers. There was not to be any kind of communication between them. The other people who worked there who were scattered around the State were instructed not to communicate with the parents and, just so everybody knows, they have not. I think those are kind of gestapo tactics, and I do not feel that the workers can do the job they are paid to do, to take care of these people, with these kinds of stresses.

The other thing I was concerned about was, Human Services has a lot of agencies that have backed them on support to close Johnstone. Where are these agencies in support of the 150 people who are not going into the community; that are going to the larger facilities? I don't hear anyone getting up and saying, "What about these 150 people?" Those are our concerns. That is fine for the people who are going into the community, but everybody is forgetting about this wonderful plan that originally was for the budget, and then originally to deinstitutionalize, when more than half are not going into the community.

The other thing is, people have testified today about the fact that they have been in institutions, or they don't want their child to end up that way. Every person with a disability is unique, and each of us parents at Johnstone made a decision. A lot of these kids have not been there since birth. My son didn't go there until he was almost 17 years old, and it was a decision that was painful and difficult. Even for years after this was a question: Did I do the right thing? Was it the right move for him? This is equally painful. I don't have a decision on where he is really going to go, because even if they say they have agreed to a group home, I will have to go through the whole process of disputing it. Everybody who decides what they want for their child when they are small-- I had great expectations for him when he was five years old. I thought that when he grew up he would go to a group home; he would work somewhere. He can't count money. So, a lot of factors have to be brought into this. Not everybody can make the same decision, just like everybody here cannot go to Yale or Harvard, but that does not mean that they can't go to a community college. So we have to walk before we can run.

I really hope that this Committee will realize that the process by which they are doing this is not the process that would be the correct one for each individual at Johnstone.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Ms. Archer. Any member care to ask Ms. Archer a question? (no response) Thank you for your testimony this morning.

Next will be Ellie Stone.

E L E A N O R S T O N E: I'm sorry I didn't distribute this first. (referring to written statement)

ASSEMBLYMAN WATSON: Good morning.

MS. STONE: Mr. Chairman, members of the Committee: I am Ellie Stone. I am the Executive Director--

Good afternoon, excuse me. I am the Executive Director of the State Association of Jewish Federations. Today I am here in my capacity as a volunteer serving on the State Human Services Advisory Council, and the Chairperson of the Legislative and Policy Committee. I am here today as a spokesperson for the Council, in the absence of Lou Paparozzi, the Council's Chairperson. I have been a member of the Council for over five years and, as I just said, I serve as the Chairperson of the Legislative and Policy Committee.

As you may know, the State Human Services Advisory Council is an advisory body to the Commissioner of the Department of Human Services. Its membership consists of approximately 75 human service professionals, service providers, advocates, and consumers, with a wide range of expertise on human service issues.

The State Human Services Advisory Council became interested and involved in the issues surrounding the closing of Johnstone early this year. It assigned the task of reviewing the Department of Human Services' proposal to its Legislative and Policy Committee in early April 1991. The membership of this Committee includes Dr. Elizabeth Boggs, a nationally recognized expert on services to the developmentally disabled, and others with particular expertise regarding departmental policies as they relate to the developmentally disabled. The Committee and, at a later date, the full Council received thorough briefings by key Department staff involved in the planning, including William Waldman, Deputy Commissioner, and Rob Nicholas, Director of the Division of Developmental Disabilities.

The Committee found that the Department was going about the initiative to close the facility in a thoughtfully planned manner and was engaged with the community and the parents of the residents being cared for at Johnstone to the extent of their willingness to participate. Indeed, the

Committee discussed with staff the many difficult issues that require exploration and deliberation and the total involvement of the human services community, the parents, and the residents.

The Committee reported its findings to the Council and, at its May 24, 1991 meeting, the Council voted to support the closing of the Johnstone Training and Research Center for the following reasons:

* The closing will result in a modest expansion of community-based alternatives such as group homes.

* The facility currently does not meet Federal standards that relate directly to quality of care, and the cost of the corrective actions necessary would be disproportionately excessive considering the number of residents. Its residents who still require institutional care will receive a higher level of care in facilities that meet the Federal standards.

* The staff of Johnstone, hopefully, will be relocated to other facilities, thus retaining employment while improving staff to client ratios.

* The closing will result in savings of approximately $2.5 million, with an appropriation of some $7 million that will be used to support ongoing costs of community-based programs.

* The closing has been well planned and will result in improved living conditions for the developmentally disabled clients.

However, the Council does not want to make light of the concerns being raised by parents, relatives, and family members of the Johnstone residents about the effects of the transition on their family members. In fact, many Council members are both providers of services and are very familiar with these issues, because many members have their own family members in residential facilities.

We recognize that any change in the pattern of their care will be stressful for the clients and their families. The

Council believes that in order to address the concerns of the families and ensure proper planning for each resident's continuum of care, the Department has built in several safeguards that will serve to protect them such as, as we've heard: The IHP plan, the creation of the Parents' Advisory Committee, and the involvement of both the State Association for Retarded Citizens and the Developmental Disabilities Council in the planning activities related to the closing.

The State Human Services Advisory Council has long supported the movement of the locus of care from institutional settings to community-based settings whenever appropriate for clients. In the case of Johnstone, we believe this will be the result for many clients. The Council has long supported the provision of caring facilities that meet certain standards of care. We believe this will be the result for all of Johnstone's clients. From our perspective, ICFMR certification is a quality of care issue first, and then a fiscal necessity considering the current budget climate.

In conclusion, for the reasons stated above, the State Human Services Advisory Council supported the closing of the facility at Johnstone for, first, the benefit of the clients; secondly, the fiscal integrity of the institutional care system; and finally, in need of expansion of the community-based services network that would result.

Finally, the Council urges the human services community, as a whole, the providers of these services, and these individuals who will require the services in the community, and the parents and the relatives of the current residents of Johnstone, to actively seek opportunities to involve themselves in the closure, in the process, and in the development of alternative services in the community. Working together, the results will mean a dramatic improvement, hopefully, in the quality of care of life for Johnstone's current residents.

I thank you for the opportunity.

ASSEMBLYMAN WATSON: Thank you, Ms. Stone. I have just a couple of questions to ask you.

On your last page, the top paragraph, you stated: "In conclusion, for the reasons stated above--"

MS. STONE: Right.

ASSEMBLYMAN WATSON: "--the State Human Services Advisory Council supports the closing of the facility at Johnstone for the benefit of the clients, the fiscal integrity of the institutional care system of the Department of Human Services, and the expansion of the community-based services network that would result."

I would like to ask you a question on those who have now been placed in other facilities. Has your Commission -- or Advisory Board followed up on those placements, and are you satisfied that they are getting the kind of care that you stated here?

MS. STONE: I must be honest with you. I have only received basic reports that the process is continuing; that there have been no filings of complaints on the process; and that a number of residents have gone into the community-based services. But on an individual basis, or an individual review process, I have not maintained that kind of oversight.

ASSEMBLYMAN WATSON: Do you think that is something we should be doing as an Advisory Board -- following up on the recommendations that were made by the Department itself and your Advisory Board? Or, would you wait until all have been placed and then begin to review it?

MS. STONE: I think the hearing you are having today is certainly appropriate. I think any hearings that you would determine in the interim would be appropriate. If you want and feel it is important that the State Human Services Advisory Council do a more in-depth review of the actual process that is going on now in the actual placement and in the review, I am

sure that the Legislative and Policy Committee would be glad to take that up as a position, and I would recommend it as a Chairperson that they do do that.

ASSEMBLYMAN WATSON: I would love to see that, because--

MS. STONE: We can work on that together.

ASSEMBLYMAN WATSON: --early on in our hearing this morning, Ms. Jones, I think, said that even members of the Johnstone staff who were sent out to take a look at the other facilities that maybe they would have to go to -- that the other facilities are looking down their noses at these staff members as if they do not want them there.

MS. STONE: In my area, I have to share with you, Johnson & Johnson just announced today that it is going to be closing -- where I live-- They are beginning to phase out a large plant, and there will be a lot of layoffs at that plant. Layoffs or changes are painful for just about everyone. I don't negate that. I have been laid off myself at different times, and I certainly understand that. But I think it can be looked at, and I think it should be looked at for the comfort of both the client and of the employee. I think "planning" is the operative word here. The need to have placement planning, which is what I am hearing, the Department is trying to do with the employees, and that is to be applauded. The process and the result sometimes do not always reach the planning stages. I recognize that.

ASSEMBLYMAN WATSON: Then, am I hearing you right that those from Johnstone who are going out looking at the different institutions, probably for reemployment in those institutions-- Those who are snubbing them feel that they will be coming in there and bumping them, or--

MS. STONE: I don't know whether they would be going in there to bump them. I certainly cannot speak to that, Mr. Chairman, but I can speak to the fact that every time you go

through a process like this, there is pain. That is not to be ignored or denied. If you would like us, as a Legislative and Policy Committee, to help to take a look at that, I would be glad to make that offer on how that could be better facilitated and how outplacement and reemployment could be better facilitated. I would be glad to offer my good services for that.

ASSEMBLYMAN WATSON: Thank you. This whole testimony is being transcribed. We will be making recommendations accordingly.

MS. STONE: Good for you. I like that.

ASSEMBLYMAN WATSON: I know that we have all sat here for about three hours now -- or two-and-a-half hours. I am going to call for a break at this time -- 12:30 -- in the hope that we can all return by at least a quarter of two.

MS. STONE: Would you need me afterwards, or--

ASSEMBLYMAN WATSON: Not necessarily.

MS. STONE: No, all right. Thank you very much.

(RECESS)

AFTER RECESS:

ASSEMBLYMAN WATSON: May I have your attention, please? We're ready to resume our afternoon session. First to be called is Sandra Porrata. Is there a Sandra Porrata in the room?

S A N D R A L E E P O R R A T A: Here I am.

ASSEMBLYMAN WATSON: Good afternoon.

MS. PORRATA: Good afternoon.

ASSEMBLYMAN WATSON: Would you state your name for the record, and who you're representing?

MS. PORRATA: Yes. My name is Sandy Porrata.

ASSEMBLYMAN WATSON: Okay. Would you want to begin your testimony?

MS. PORRATA: When I was 19, my mother told me she was taking me somewhere special. I knew it was far away because she packed all of my clothes. We came to a place that looked like a hospital. My mother said I was going to stay there to learn how to take care of myself. Later, someone told me I was at the Vineland State School.

It was awful. All I could do was cry and call for my mother and grandmother. I was scared because I didn't know anybody; I was all by myself. Anything I needed I had to get on my own. I lived at Vineland for 16 years.

One day I made up my mind that I was going to get out. I spoke to my caseworker and asked if I could get out. He said he would work on it.

He came back and said he had to write a letter to my mom. My mom didn't want me home; she wanted to keep me away from my family. But I still wanted out.

One day, my caseworker called me into the office. He said he found a lady who needed someone to live with her. A few weeks went by and then she came. Her name was Mary.

I liked her very much. Mary said she needed somebody to live with her and she picked me. I told her I would like to live with her until I got used to being on the outside.

I liked it with Mary. I had my own room, my own TV, my own telephone -- everything I wanted and never had before. I was independent; I could come and go as I pleased. Anything was better than Vineland.

I started going to United Cerebral Palsy's adult program and learned cooking and other things. I lived with Mary for four years, and then it was time to leave and do more with my life.

In 1986, I met my husband, Junior, at camp. We got married and moved to the South Bronx for awhile, but it was a bad place to live; we got robbed every month. Now we live in Long Branch, New Jersey.

It was hard to leave Vineland because I had friends there. When I left, I cried because I knew people there who weren't going to get out. It was very hard, very emotional. I cried.

I was scared to get out; very scared to be around people like you. I didn't talk. I didn't go places. I was afraid of people looking at me and wondering what I was doing there.

But now, I don't care what people think. I'm normal. I've got a mind. I know what to say around people.

You have to make up your mind. You have to want to get out. And if you do, make your move. You've got to live now, or you are going to be developmentally disabled and die in an institution.

ASSEMBLYMAN WATSON: Thank you, Ms. Porrata. Your husband's name is?

MS. PORRATA: This is my husband.

J O S E P O R R A T A: Jose. Glad to meet you.

ASSEMBLYMAN WATSON: Jose? Thank you for your testimony this afternoon.

MR. PORRATA: Thank you.

ASSEMBLYMAN WATSON: We have your written testimony here, and we will make it a part of the record.

MS. PORRATA: Thank you.

ASSEMBLYMAN WATSON: Thank you.

Dr. Deborah Spitalnik? Good afternoon.

D E B O R A H M. S P I T A L N I K, Ph.D.: Good afternoon.

ASSEMBLYMAN WATSON: Would you state your name for the record, and who you represent?

DR. SPITALNIK: Yes. My name is Deborah Spitalnik, and I'm the Director of the University Affiliated Program at the University of Medicine and Dentistry of New Jersey.

ASSEMBLYMAN WATSON: Thank you. You may continue.

DR. SPITALNIK: Thank you. I appreciate the opportunity to testify before you today. The University Affiliated Program of New Jersey is one of a network of 45 federally designated programs nationwide providing state-of-the-art training, technical assistance, service, research, and information dissemination in developmental disabilities.

I want to speak about Johnstone today in the context of national activities in developmental disabilities. In my role as Director of the UAP in New Jersey and serving as President of the American Association of University Affiliated Programs, I am acutely aware of the growing national vision of full participation in community life for people with developmental disabilities and the affirmative steps we must take in New Jersey, as we are lagging behind where we must be.

The passage of the Americans with Disabilities Act in 1990, with its sweeping civil rights protection, mandates the need for accommodation in all aspects of society to enable persons with disabilities, including people with developmental disabilities, to be full participants in community life. This landmark legislation came into being in recognition of the discrimination which accrues to people with disabilities and the consensus among the American people that it is time to build a more inclusive society.

The American Association on Mental Retardation, the oldest established professional organization in mental retardation, recognizes the importance of community life in its newly revised definition of mental retardation. This definition established community as the context for the measurement of mental retardation and assumes the necessity of community life for the growth and enhancement of skills for persons with mental retardation.

Through our growing experience in New Jersey and nationwide, life in the community with appropriate and adequate

supports, enables persons with developmental disabilities to express their capacities, capabilities, and gifts. Over 32,000 individuals with mental retardation are working in supported employment across the country. Over 100,000 persons live in small community residences across the country.

Increasingly, persons with developmental disabilities are telling us, directly and sometimes indirectly, that they aspire to the same things in their lives as we all aspire towards; a place to live that is truly one's own, a job, more independence, choice, and more relationships.

We have the ability to affect these outcomes for people with developmental disabilities, but in New Jersey we are lagging behind. Despite the self-image we hold as a State as progressive, forward thinking, and maintaining life quality for our State's citizens, in the forward movement of services for persons with mental retardation we are lagging behind the nation.

With the development of smaller community based services and supports nationally, has been the reduction in larger congregate residential facilities. New Jersey ranked as the fourth highest State in the country in terms of the numbers of persons institutionalized. Expressed differently, 46 states have fewer numbers of persons institutionalized. It should also be noted that here in New Jersey in our institutional beds, 1500 of these beds do not meet Federal standards.

New Jersey ranks 34th in the percentage of reduction of our institutional beds for the period of the mid- to late-'80s.

New Jersey is 27th in the nation in spending in mental retardation and developmental disabilities. What we do spend, we persist in a disproportionately higher rate of spending for institutions rather than the community.

Significant institutional closings have occurred or are planned in other states. New Hampshire and the District of

Columbia no longer have any institutions; they are totally community based.

It is time for us in New Jersey to catch up. The closing of Johnstone represents an important step toward achieving our rightful place as a State that demonstrates its commitment to community services and lives of quality for persons with mental retardation and their families.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Doctor. Doctor, thank you for your testimony.

Mr. Gerry Ruane?

G E R A R D R U A N E: Good afternoon, Chair.

ASSEMBLYMAN WATSON: Good afternoon. Would you state your name and who you represent?

MR. RUANE: My name is Gerry Ruane. I'm a friend of a developmentally disabled individual. I don't have any professional tie with him other than the fact that I serve as his financial guardian.

I've come to know this situation about Johnstone through a prior witness this morning, Ms. Hoetzel. I felt it was my duty to come down here and express my views.

This fellow, (name deleted), the friend of mine, has been a client of DDD for the past three years -- two-and-a-half years, I'm sorry. I feel that the closing of Johnstone will adversely affect him in the fact that he is part of the whole system. One extra body in that system affects how he'll be placed and how he's treated.

What I'm getting at here is, despite everyone's commitment to treat the developmentally disabled with no less than the utmost dignity -- and I'm not pointing a finger at the Commissioner, at the Assembly, or at anyone in particular -- but the system has failed.

What I'm getting at is: My friend, who-- Two-and-a-half years ago I got involved in his case because his

mother, at 75 years old, developed Alzheimer's disease and he was left by himself in an apartment, and he is mentally retarded. It took a long time for DDD to become involved. We went to court, fought it for six months, and finally he was accepted as a client. He was placed in a group home and because of the separation from his mother, acted out. For the past two years and two months he has been in Bergen Pines Hospital.

How this ties into E. R. Johnstone is-- I'm afraid for the people who are involved in the closing. I'm afraid that they're not going to be placed correctly.

My friend has sat in a psychiatric ward as a dead body for two years and two months. He has not been seen by anybody. He sat there, has been medicated, and has gained 75 pounds. This ticks me off. He has had no services, whatsoever. He is mentally retarded, and he is a client of DDD. If it happens to him because he has no representative, because, maybe, I haven't been the vocal force that I should be-- Maybe I'm going to have to get a little more involved and come to these meetings. It's a bit of a hardship for me as it is for everybody here, but I feel that it has to be known that people fall between the cracks. There are the good stories, which the Commissioner pointed out, and I don't want to point fingers at him or anybody, as I said, because I know it's a tough, tough system. But it has to be perfected to a point of being better than it is. When a gentleman sits in a place for two-and-a-half years and is not touched or treated by DDD-- If Bergen Pines Hospital didn't accept him and welcome him as a family member in a psychiatric ward which, to me, is not a good setting for somebody who has growth potential -- it's a 21-day placement -- well, then we have some serious problems.

I feel the closing of E. R. Johnstone will affect him as well as many others.

In closing, I'd like to just state that some-- You know, I don't know how I can be a part of it, or you can, but there has to be better placements. There has to be better guidelines to the plans with which they release and handle the patients. There are two many people under certain caseworkers. They don't have the time to get over there. I don't know how many people are out there without an interested party. The reason I became involved was because there's nobody else. This gentleman has a mother who's in a nursing home and he has absolutely no other family. If this case can occur with my friend, I'm sure it can occur with a lot of others.

I just want to make that point, that I'd like to see a lot more activity in developing plans that are meaningful and not just dumping plans. My friend was dumped, and I regret that immensely. Seventy pounds and just medication for two years is not the way to treat somebody who has the potential to be a lot better off in society.

Thank you for your time.

ASSEMBLYMAN WATSON: Thank you Mr. Ruane. I think the basis for these hearings are to listen and do something about it. Thank you for appearing here this afternoon.

Next is Mr. Harry Randall.

H A R R Y R A N D A L L: Thank you very much. I welcome the opportunity to speak. I'm Harry Randall of Fair Lawn, speaking for many families of people with mental retardation at North Jersey Developmental Center and other developmental centers. I aim to reflect their views, but I accept responsibility for my words here.

I should also say I'm a long time member of the ARC New Jersey State Board of Directors and a long time member of the Bergen Passaic ARC. I know of a number of fellow members in both places who agree with the point of view that I'm going to present, and we're a number even if we're a minority.

First, some conclusions:

1) Closing the Johnstone Training and Research Center, or any other developmental center in the foreseeable future, is unconscionable, given the large waiting list of retarded people with urgent needs, and given the lack of better or even appropriate alternative facilities for those now served in these centers.

2) And this contains a point I want particularly to make because it's a point that's been missed in most of the discussion by most people here, and elsewhere. Simplistic programs have been advocated by some which ignored the important differences between those with mild or moderate retardation and those with severe or profound retardation or with multiple disabilities. This is the big factor missing in most discussions. Those with lesser retardation vastly outnumber those with greater disabilities, so the latter are easily neglected in planning. Those with greater disabilities are the very ones that developmental centers increasingly are serving and can serve better than existing alternatives.

3) Meeting arbitrary numbers goals is driving many transfers of clients, not improved life for the clients, in spite of lip service to the latter.

4) Some who should be advocates for all are following lopsided and divisive dogma which fails to serve the most disabled clients, instead of serving the full range of needs and conditions through a full spectrum of different services. These dogmatists have erected an arbitrary dividing line between larger facilities and smaller ones, ignoring clients' differing needs -- and the wishes of clients and their families, I would add.

5) Services for people with mental retardation in New Jersey are vastly underfunded and are deteriorating -- visibly deteriorating -- whether they live at home, in group homes, in supervised apartments, in foster homes, or in developmental centers. New Jersey can afford much better, as the State with

the second highest per capita income in the country which claims the world's highest standard of living. It's up to you legislators, of whatever party, to fund these and other deteriorating human services and to give leadership in explaining the rightness of this, the necessity of this to our fellow taxpayers.

6) Closing developmental centers will not save money for community services, in spite of claims to the contrary. It would simply transfer the higher costs for those who need the most care, while reducing their access to services. There should be no competition between groups, between categories, in the pursuit of dollars. There should be enough funds to serve all in the best possible way.

Now to back up these conclusions: We've heard some one-sided arguments for closing developmental centers largely based on failure to recognize this range of disabilities and needs and wishes within the mental retardation spectrum -- roughly classed as mild, moderate, severe, and profound retardation. In addition there are those with multiple disabilities including epilepsy, blindness, paraplegia, autism, problem behaviors, and chronic illness.

Some advocates have a tendency to generalize by portraying all people with retardation as matching public relations prototypes who can potentially ride a bus on their own, hold a job, learn in a classroom, prepare meals, and speak understandably to others. Some people we've heard today address only those -- a majority but not everybody. This by-passes those who can't walk, or can't talk, or can't dress themselves, or can't even feed themselves, or take care of their toilet needs. Some can function only at a 6-year-old level, some like 4-year-olds, some like 2-year-olds, and a few like 6-month olds. To speak, for instance, of their "right to take risks" or their right to hold a job, is ridiculous. Would we want our normal 3-year-olds or 4-year-olds to go shopping by

bus on their own, or cross a busy street alone? Levels of permissiveness and choice need to be governed by differences in functional levels.

In the opinion of many, including those of us in the parents' associations of developmental centers, many clients with severe or profound mental retardation -- not all -- can be served best in larger facilities, where more direct care and central medical, nursing, speech therapy, physical therapy, behavior modification, and skill training can be provided with economies of size. At the same time, they can take part -- take as much part in community living as people with these disabilities could experience anywhere.

As has been stated recently by various experts and caregivers, it isn't the size of the living facility that matters, but the adequacy and quality of the care provided and the life lived.

We parents worry over long-range plans that endorse the closing of Johnstone as a prelude to closing all other developmental centers, as this would wipe out adequate support for the clients we're describing. Some who should know better have jumped onto the pendulum of closing all larger facilities. I think they're blind in one eye.

We ask you to legislate for all retarded people according to their unfilled needs -- some of them desperate. All facilities suffer underfunding, and all should be improved. Some, no doubt, should be replaced in time by better and different facilities -- when these are funded, built, staffed, and tested.

Some years ago, group homes were launched on a growing scale and were supposed to be the coming answer to the needs of people with retardation. Though not nearly enough have been established, they have been of benefit to many, unsuccessful for some, and an unsatisfactory facility for others who proved to manage better elsewhere -- some in supervised apartments, for instance, and others back in developmental centers.

In my memory, services to people with mental retardation have always been underfunded in New Jersey, including the developmental centers, and today the underfunding is much greater.

It is a false argument that we have two State systems to serve retarded people and can afford only one, so we must eliminate one. We have, and need, only one; with enough subdivisions to provide a spectrum of facilities to serve different needs in different ways. These include support for those living with families, independent living arrangements, supervised apartments, group homes, foster homes of several types, and developmental centers.

It is an artificial division to call some of these "community" and others "not community." Today's developmental centers are not the isolated, restrictive, custodial institutions of earlier years. My severely retarded daughter at North Jersey is taken regularly off campus to workshops, restaurants, and shopping. She visits other people's houses and has a lively, gregarious social life with parties, dances, and special olympic athletics. And she chooses decorations in her own room, and a lot of other things.

Some people point an accusing finger at developmental centers because, despite the marked reduction of their population, per capita costs have risen. But note that the population of these centers has come to consist more and more of those with the greatest disabilities, who need the greatest care and the largest direct-care staffs. So the increase in average per capita cost was inevitable.

Assuming that enough adequate small facilities will be established for those who can actually live better in them, when such clients are transferred out, the center populations can expect to consist entirely of those with profound retardation or multiple disabilities. And the per capita will understandably go higher yet. But wherever these most fragile

people live or move, the higher cost of care will move with them, unless they are shuttled off into inappropriate foster homes with poor care and neglect.

Very few group homes exist that are tailored to the needs of multiply disabled clients or those with behavior problems. In these few, the costs of staffing and services have proven considerably higher. I'm told that one ARC group home is no longer accepting those with the behavior problems it was originally designed to serve. Where, then?

We are told by several experienced people who have investigated costs, that care in group homes proves to be just about the same as in the centers. So cost is ruled out as a legitimate argument for moving people from centers to group homes. That leaves the really valid measuring stick of quality of life. For some of those who now live in the centers, life could be improved in a group home; for others, not so. This will vary greatly with individual conditions and needs.

Moving is one of the most traumatic events in anyone's life. This is at least as true for people with severe disabilities. So transfers should be planned to meet real needs and with the prospect of real improvement before people are moved; not for the dogmatic or political motives, or to suit an arbitrary numbers game.

Most emphatically, we deplore the rush to promote cheap "skill-development" foster homes to house many people moving from developmental centers, concurrent with the influx of clients transferred from Johnstone. This reliance on skill-development homes is to us an unsatisfactory substitute for the group homes which are lacking, and where many of these clients could have been more adequately placed.

Such homes were introduced to us a few years ago with the explanation that they were to provide a relatively short period of social adjustment and behavior modification by trained experts to prepare a few selected clients for living in

a group home. Now their function and purpose has evidently changed to a long-term, cost-cutting arrangement for many. This appears to be another case of expediency and budget determining policy, rather than designing policy to serve clients. And numbers again appear to be determining how many and who will be placed in these foster homes rather than their suitability for individual needs -- whatever claims are made otherwise.

We worry about our sons and daughters being sent to these foster homes in the possible future because we see a lack of adequate training for handling their special needs, a lack of adequate frequent supervision and inspection -- claims to the contrary notwithstanding -- and the lack of enough staff to blow the whistle in case of cruelty or abuse, which are known to occur too often in foster homes.

We call on you to appropriate enough funds to establish the group homes and other community services that are needed, and to support and fund all developmental centers for those who will continue to need their special services. And I appeal, again, for a bridge between the people who have spoken on opposite sides of a division, a division which I think is unnecessary. We need, all, to broaden our perspectives and include everyone as most suitable.

I thank you very much.

ASSEMBLYMAN WATSON: And thank you, Mr. Randall, for your testimony.

Next is Mr. Klein. Don Klein from CWA Local No. 1040.

D O N A L D L. K L E I N: Thank you, Mr. Chairman. For the record, it's Don Klein, CWA Local No. 1040.

It was just 30 short years ago that Johnstone Training and Research Center was recognized nationwide as a prestigious facility dedicated not only to the daily care of the mentally retarded, but to future client needs, through its research and development components. As well, the same applied to its

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sister institution, The New Jersey Neuro-Psychiatric Institute at Skillman, then dedicated to the care of the mentally ill. These facilities each published more than 25 professional papers per year. Highly trained professionals provided top quality services for clients. Pride in achievement was the hallmark. These facilities continue to have highly trained professionals and dedicated staff, despite the interference by State officials.

State officials, for over 30 years, have abandoned the mentally ill and developmentally disabled. Institutional buildings constructed by artisans have been sinfully left to decay. Throngs of brilliant social scientists have long disappeared from the campuses, leaving a skeleton staff of dedicated professionals. It is evident that recent administrations don't care about the State's most vulnerable citizens. They only care about their own political careers and are blinded by dollar signs. There's money for their State offices, far removed from client cottages.

Due to the State's unforgivable neglect, they are now evicting patients from their homes; homes that blind and mentally retarded clients have taken many years to become accustomed to. The State is ripping apart long established friendships. Some patients have no families; their family are peers and staff. Life changes are difficult for so-called normals. However, changes for developmentally disabled are devastating.

The first to be impacted by budget deficits are those with no voice. Guarantees to maintain vital public services only appear during political campaigns.

Commissioner Alan Gibbs and Robert Nicholas, Director of the Division of Developmental Disabilities, have betrayed Johnstone clients, staff, and their respective families. These State officials have subjected developmentally disabled citizens to what amounts to being psychological abuse. These

are the same individuals who have supposedly been entrusted to protect their rights. Robert Nicholas publicly stated that non accredited units at existing facilities could have been phased out rather than the full closure of Johnstone Training and Research Center. They mistakenly opted for the latter alternative which has resulted in utter chaos in so many lives.

The 1992 DHS proposed budget cites overcrowding at North Princeton Developmental Center, where Johnstone clients are slotted for transfer. Additional placement changes are necessary, and a clear possibility exists that Johnstone clients will again be displaced.

This Committee cannot undo the pain that has already been inflicted. However, it is not too late to prevent a tragedy -- the closing of Johnstone Training and Research Center. And this would be a tragedy.

I would just like to add: There are a lot of groups who are involved as a union, in organizing so-called nonprofit groups in the community. Those very same groups who can speak here so philanthropically have their administrators making $80,000-plus per year while the workers are making very low wages, who use State funds to hire union-busting attorneys and whose care is very questionable.

So, it is not a panacea. The State has an obligation to work for funding of these developmental centers which provide very valuable services.

Thank you.

ASSEMBLYMAN WATSON: Thank you, this afternoon, for your testimony.

Next is Ms. Adelaide Daskan, and I think with Ms. Daskan is Steve, Kenny and Diane.

A D E L A I D E D A S K A N: Good afternoon. My name is Adelaide Daskan. I'm from Totowa, New Jersey. I've been in an institution for five years, and staff has been helping us taking a lot of people out from institutions. Being that

Johnstone is closing, I wish that Johnstone will close altogether and more group homes and more supervised apartments can be built up all over the place, because staff and Board of Directors at the AAMH is also trying to help institution people like us get out in the community, too. We would like more group homes and more supervised apartments and more family care to come up through the years.

ASSEMBLYMAN WATSON: Thank you.

Would you state your name for the record, please?

D I A N E J O N E S: My name is Diane Jones, and I've lived in Johnstone for nine years and I would love Johnstone to close because a lot of people will get hurt over there and a lot of people -- I see for myself, I was in Johnstone -- got hurt and brutalized, and I would love to get them out. I would love to get Johnstone closed. And I hate people who hear Johnstone -- to keep it open -- because it's not right. The people over there have rights for them to get out of Johnstone. They should be living out in the community, just like I am. I live in Hillside, New Jersey, and I'd love to have them over there in supervised apartments, group homes, family care in all units, instead of Johnstone and Totowa or any institution.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Diane.

And your name, sir?

S T E V E N A G O L I A: My name is Steven Agolia and I'm a member of the Linden Supervised Apartment Program of Linden, New Jersey.

I have never been in an institution before, but based on what I have heard about some of the disabled members -- that are blind, deaf, in wheelchairs, mentally retarded -- I still feel there's a place for them, more so than just an institution.

I was listening to some of the other representatives speaking, you know, about their sons and daughters and

guardians and stuff, and I just don't think it's right to hold them back because they're mentally retarded, or can't walk, or can't see, or can't -- whatever.

I think that Johnstone may have been a good place to start, but now it is no more. Totowa is the same thing because Totowa, Johnstone, and the rest of them, they don't provide any kind of services for people such as those with mental, physical or verbal disabilities that need outside setting places, such as supervised apartments or group homes.

In closing, I would just like to say that, you know, more people on the staff, and on the outside, should get involved and just-- I wouldn't go right ahead and say, you know, damn everybody else, but I would say get everybody in the situation-- Everybody can work together and, hopefully, do what's in the best interest for those that are less fortunate, that have mentally retarded and disability problems, and do what's in their best interest. And hopefully, we can make it a better place where more people can get involved and, you know, help out, and maybe we can see a better world.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Steve.

Your name, sir?

K E N N Y A L L E N: My name is Kenny Allen and I've been in Johnstone for quite some time and I've been in there and I've-- I am now a free person, and I am now where I can do more than I've been doing for a good long time. I am now enjoying my freedom instead of being in an institution. They were very strict there. It's not a very pleasant place to be right now, and I would not want to be there to visit at any time or, you know, at a former time. I would love to see them out in the community and get a better apartment, or whatever. You know, an apartment or live in-- At least as long as they're living on the outside, away from Johnstone.

ASSEMBLYMAN WATSON: Thank you, Kenny, for your testimony this afternoon.

MR. ALLEN: You're quite welcome.

Richard Sheridan? (no response)

M A R Y A N N N E D E R: (from the audience) No, I'm Mary Ann Neder, Public Relations for the ARC. Is there also a person on there by the name of Anthony Brown?

ASSEMBLYMAN WATSON: Anthony Brown? Tony Brown.

MS. NEDER: Yes, is he--

ASSEMBLYMAN WATSON: He's going to be called up.

MS. NEDER: Okay. Would you-- Mr. Sheridan is the Executive--

ASSEMBLYMAN WATSON: Just speak on the microphone.

MS. NEDER: Does the forum wish me to speak in place of Mr. Sheridan?

ASSEMBLYMAN WATSON: Well, Mr. Sheridan is on for the-- If he's not here, we will listen to the next person. We'll also bring on Mr. Brown.

MS. NEDER: Thank you.

ASSEMBLYMAN WATSON: Next is Janet San Clemente, Barbara Coppens, and Colleen Fraser. Do you want the three to sit there? Are the three of you here?

You're Barbara Coppens?

B A R B A R A C O P P E N S: Yes.

J A N E T S A N C L E M E N T E: (off microphone) I'm Janet San Clemente.

ASSEMBLYMAN WATSON: Are you going to speak?

MS. SAN CLEMENTE: Yes. Do you want me to speak first?

ASSEMBLYMAN WATSON: You can take a seat. And how about Colleen Fraser? Do we have a chair there for Colleen?

ASSEMBLYMAN WATSON: All right. You're the Chairman, Colleen?

C O L L E E N L. F R A S E R: Yes, I am.

ASSEMBLYMAN WATSON: Okay. Do you want to begin?

MS. FRASER: Did you want Janice to begin, or myself?

ASSEMBLYMAN WATSON: Well, that's between the three of you.

MS. FRASER: Okay. I'd like to make an initial statement as a person with a disability -- a developmental disability -- a person who's an advocate for people with disabilities. And my original statement is that the people with developmental disabilities that got here today, got here at great expense to themselves energywise, dignitywise, all other kinds of ways -- to come to a building that is not accessible to the hearing impaired, that is not accessible to people who use wheelchairs. There is, in fact, a ramp. It is not indicated where it is at the front of the building. You have to go around the whole building to get in here. That is a slap in the face to people with disabilities, and I'd like you to note that.

ASSEMBLYMAN WATSON: I just want to, for the record, state that I was also upset when I saw that there was no barrier here and that you would have to go around to the front. I agree with your feelings.

MS. FRASER: And I think that I would like that noted in the record because that is--

ASSEMBLYMAN WATSON: It's noted. It's being transcribed.

MS. FRASER: Okay. I'm Colleen Fraser. I'm the Chairperson at the Developmental Disabilities Council for the State of New Jersey.

I'm quite distressed today at the direction that this hearing has taken. And I think that the direction that this hearing has taken is a slap in the face to people with developmental disabilities in this State of New Jersey.

I came here today to talk about the quality of life issues for people with disabilities, particularly those people who live, by necessity at this point -- we are trying to plan around to get them out of there -- in residential centers.

This hearing and the direction it's taken toward discussing labor union concerns and not quality of life issues for people with disabilities--

ASSEMBLYMAN WATSON: Just a moment. Just a moment. Just a moment. Just a moment. I'm not going to sit here and listen to that kind of rhetoric. We called this meeting here not for labor unions. We called this meeting for the benefit of the people of Johnstone. Employees, of course, we're interested in, if they're being muzzled. We called this meeting for the care, the proper care-- And I want you to know something else. I'm for group homes, but I'm only for group homes if they're going to get the level of care that was given to them at Johnstone. I have visited Johnstone. And on top of that, I'm not here to be insulted by calling this meeting-- I'm the Chair. If you have a statement to make other than--

MS. FRASER: Mr. Chairman, I did not put you down for calling the meeting. What I was upset with was the direction that the meeting has taken.

ASSEMBLYMAN WATSON: Well, I don't want you to be making references to this meeting was called for the union. It was not.

MS. FRASER: No, that is not what I said and I'd like that clarified. What I said was that the direction-- When this meeting was called, we were happy for the opportunity to come and talk about quality of life issues.

ASSEMBLYMAN WATSON: Well, then it's not a slap in the face to you.

MS. FRASER: The direction that it has taken is. And I'd like to finish my statement, if I might? Shall I continue?

ASSEMBLYMAN WATSON: Yes. You have a written statement there?

MS. FRASER: Yes. This hearing has serious and needlessly damaging consequences for the people with developmental disabilities affected by it. It creates the

impression that the decision to close Johnstone can be overturned. That raises false hopes in those who still oppose it, raises needless anxieties in the minds of those who are intimately involved in the closing -- the people who live at Johnstone and the people who are helping them prepare for better lives elsewhere, and it reopens a conflict that has badly divided the State's developmental disability community just when the wounds of that conflict were beginning to heal.

The Developmental Disabilities Council is federally mandated to advise the State Legislature, the Governor, and the public on policies which affect people with developmental disabilities. As such, the Council is bound to protest the harm this hearing may cause.

The public debate over closing Johnstone was settled last summer. In that debate, every responsible voice agreed with the Division of Developmental Disabilities, the Department of Human Services, the Governor, and the State Senate that Johnstone should close.

The Association of Retarded Citizens of New Jersey agreed. UCP -- United Cerebral Palsy -- agreed. That is not here in the statement. The overwhelming majority of its ten thousand members at ARC are parents of people with mental retardation. The New Jersey Developmental Disabilities agreed. The majority of its members are people with developmental disabilities and their families. Half a dozen other statewide organizations that serve people with developmental disabilities or plan and deliver other human services agreed.

The process of closing Johnstone is well under way. The Division's plan for closing it has been updated and reviewed by all interested parties and submitted to the State Legislature. An extensive process for monitoring that plan is in place and being aggressively implemented.

More importantly-- When this was written, it was 40 people. I heard today it was 51 people had already left Johnstone for better lives than they lived before. They know it, and their families know it. No one has objected to any of these placements or taken any action to oppose any of them.

This hearing diverts energy and attention from the important tasks of monitoring the closing of Johnstone to make sure that every person affected by it will live a better life and providing support to them and their families during their transition to that better life.

The hearing diverts all of us from the unfinished business raised by the State's decision to close Johnstone in the first place. That decision was driven by the recognition that New Jersey's system of care for people with developmental disabilities is in need of major reform.

The ten large institutions the Division runs form the decaying centerpiece of that system. They were built to serve 9000 people. They now serve less than 5000, at least 1500 of whom have been determined able to live in the community. A system built to serve 9000 people cannot be sustained unchanged to serve less than 3500.

Change must occur. That change must protect the people with developmental disabilities who we do not have the wisdom, knowledge, or will to serve adequately in the community. That change must acknowledge the legitimate needs of the people working in that antiquated system. That change must recognize the legitimate claims of other people with developmental disabilities who are denied services today because resources are lacking to serve them.

That change requires hard decisions, hard thinking, and hard work. It requires the best in all of us.

The Council calls on all responsible members of the developmental disabilities community to move beyond the divisiveness this hearing fosters and concentrate on the difficult but constructive tasks that now confront us.

I also have some comments that I was asked to carry from a self advocacy conference. As part of my responsibilities as the Chair of the Council, I go around and visit people with developmental disabilities all the time.

I was at a gathering of 120 people on Saturday last. It was a great day. About 80% of those people used to live in some institutional placement. There was structured discussion of some questions: What is self advocacy? What are your ideas about employment? The question that was asked about institutions was: What are your ideas about State institutions? Should they be closed, or are they necessary? And we were going to talk about both sides.

I just have a couple of comments. They asked me to bring them here today. One was-- This man is 73 years old: "I was at New Lisbon. In the winter we were very cold. We had to sleep on the floor. There was no heat."

I have another question here: "How long will the politicians wait to plan to close them? Until everybody's dead?"

Another one was: "I was beat up a lot at Johnstone. They didn't give you food when you were in the quiet room."

And the last that I'll give you is a person with a very severe speech disability who said: "I hated it there." When asked what did he hate, he said, "Everything."

I just brought that to you from the self advocates because they wanted you to hear it.

Thank you.

ASSEMBLYMAN WATSON: Thank you.

Just for the record, when you talk about this Committee hearing today as being a hearing that is against what you and the processes are for, I want you to know, as far as monitoring, it's our duty, responsibility as a Committee, to monitor you -- to monitor the Department, and at least there's another side that's looking out for the interests of the people

of this State. Now we're sitting here, as this Committee, calling this meeting together to get facts, to get your facts, to get the facts from the other side, and then it's up to us to make some recommendations. That's our responsibility. But when you began to slant that responsibility of ours, I think that's an insult to this Committee.

MS. FRASER: That was not my intention, Mr. Watson.

ASSEMBLYMAN WATSON: Well, I hope not. Thank you for your testimony.

MS. FRASER: I would like to comment, though, that the Developmental Disabilities Council is federally mandated to monitor and is expending dollars to monitor. We're keeping very close contact with those people and it's our Federal responsibility to do that.

Also, most of the testimony--

ASSEMBLYMAN WATSON: Well, that's also your responsibility. I acknowledge that. But you must also acknowledge the responsibility of the Legislature.

MS. FRASER: I absolutely do. That's why I'm here today, or else I wouldn't be here today, because all of the things that I've heard here today, I heard back in June. There is no new information except on the people who have been moved, so-- I've heard everything back in June that I've heard today.

ASSEMBLYMAN WATSON: Well, that's an awful lot. Because 51 people have moved. We want to hear about that. That's new. That's different than what is was when you sat here in June.

MS. FRASER: One piece of information.

ASSEMBLYMAN WATSON: Yes. Would you state your name for the record, please?

MS. SAN CLEMENTE: My name is Janet San Clemente. I reside in Haskell; that's in Passaic County, way up north New Jersey. I feel like I've been up forever.

Anyway, my daughter -- I have a daughter that's developmentally disabled. She has autism. She has been in developmental centers and she's also been in Greystone Psychiatric Hospital. Presently we're hoping she'll be going into a group home under the Eden programs of Princeton within the next six months or so, which is a blessing. She's very happy to be getting out of the developmental center.

Somehow, that stigma just never goes away. There are many things that go on. I did give a presentation before the Legislature back in 1989 on these same issues. There's abuses, there are problems. There is no real life in developmental centers as there is in a community setting, and this is very important.

We're talking about human beings here -- all human beings, and I think they deserve the right to make choices and to be able to live their lives in dignity. And this world is a challenge for all of our developmentally disabled -- every day. And they meet those challenges and they get past them. I think that we have to look at what's happening. Our world is changing; we must let them be a part of it. We have to grow and become one. We are a nation that cares, that has compassion. We do this for others that are not in this country and I think we must think right here, first on a State level, and then nationally. This begins here; right here, where our legislators are listening.

The Johnstone center is not a healthy support system. It fosters dependence; not independence, just like all the centers do. It is time to downgrade antiquated facilities and institutions, and make life more community oriented. In the community the folks can participate fully in all phases of life, both in the home or apartment, as well as at work and in social settings -- from the home where they cook and clean, and where they go to work, and to community socials, fundraisers, town clean up, and a full community life. This living arrangement enriches everyone's life.

Much has been written since the Developmental Disabilitites Council made the decision to close Johnstone -- concerns that have been, and are being, addressed. We must move forward with care, compassion and with understanding. Our developmentally disabled folks want to be a part of a full community life and it begins with an atmosphere of family, home, job, and the community. I think it can be a reality. I think all of us think it could be a reality, so let's make it so.

ASSEMBLYMAN WATSON: Thank you, Ms. San Clemente. Ms. Barbara Coppens?

MS. COPPENS: My name is Barbara Coppens. I am on the Budget Committee for DDD. What I feel about is, I have been to Johnstone a couple of times, meeting with people, and helping them to start a group. Some of them said they were ready to get out -- ready to live out in the community and get a competitive job like me. I was living in Vineland for 16 years. Then I moved out to a group home. Then from there I moved into supervised apartments, but now I have my own apartment. I am very pleased, because when you are in an institution, it is like you don't get any freedoms. You know, you can't come and go as you please. But when you are out in the community, you can come and go as you please.

I work for Hyatt Hotels Incorporated. I get to travel to different Hyatts 12 nights a year -- 12 days a year for free, because I work for that company. I would like to see some of these people get a competitive job, if they do get out and live in the community; to make that real money, earn that real pay, just like what I'm doing.

I feel that some of them are able to get out and live in the community, just like me. That is what I feel about it. Thank you very much. I'm glad I had the opportunity to come up to speak -- to do the testifying.

ASSEMBLYMAN WATSON: It is nice having you this afternoon.

MS. COPPENS: Thank you. And besides, living out in the community is different than living in an institution, because living in an institution is like being locked up in prison. But living out in the community, you're not. You're out in freedom. Thanks again.

ASSEMBLYMAN WATSON: Thank you. Next, Tom Blatner. Mr. Blatner?

T H O M A S B L A T N E R: Assemblyman, how are you?

ASSEMBLYMAN WATSON: Fine. Please state your name for the record, Tom.

MR. BLATNER: My name is Tom Blatner. I am here today representing the People Count Coalition, which is an organization which has now grown to almost 150 statewide organizations representing literally thousands of local organizations and people.

I am not going to take a lot of your time today, because I know you have a busy schedule, and experts before me have really made most of the points we wanted to make.

People Count is an organization that came together around the notion that people really deserve a shot to live as freely as possible, as normally as possible, and as close to their own homes -- or in their own homes or in their own communities. In looking at this Johnstone situation, we have three points we want to make: The first is, in terms of public policy, in terms of fiscal policy, and in terms of what is right for people, we support the closing of Johnstone. We think it is the right thing to do; we think it is the smart thing to do; and we think it is the prudent thing to do. I think the testimony about the people who have left is very compelling.

We do think some of the things we have heard today about what has happened to people who have left-- Certainly we want more information about that. I think, Assemblyman, your idea about there being a public monitoring of what happens to

people as they leave is a very important idea. I think that without your Committee doing that, a lot of times things fall through the cracks. So I think that is one thing that we would definitely support.

Secondly, we want to talk a little bit about how things might have been different. I think it is one thing, you know, when a State government runs things in a closed way -- an institutional way -- it is fine that you can make decisions that affect people. You don't really have to ask anybody. But I think, you know, from what I heard of a Committee hearing that is going on down the hallway, a lot of people right now are concerned not so much about what is happening, but the way it is happening. I think if the process of going about this closing had been handled a little differently, I think maybe this hearing might not have been necessary to call in the first place.

People Count, two years ago, called for a formal partnership in the move from an institutional system to a community-based system. I happen to do a lot of consulting, not only in New Jersey but outside of New Jersey. Every single problem that has come up in the course of this hearing is normal. Parents are very worried; parents are very concerned. The people whose jobs are threatened are obviously going to be concerned about their employment, as anybody is. Communities which are going to accept people are worried.

What we would rather have seen, and what we are calling for as these kinds of projects move ahead, is, even though it is more difficult, get everybody in one room who is going to be affected, you know, whether it is the public employees' unions or the nonprofit sector or parents or residents, and plan the thing together, and stay in the room long enough so you work out the solutions in the planning process, so when they go about happening, there have been some decisions made before things start to happen.

I honestly think that had the planning process been more participatory and more open, a lot of things that have come up today could have been solved before this hearing was necessary.

So, while we are very, very supportive of the closing of Johnstone, and we think it is the proper thing to do, we think that unless there is a formal way to institutionalize participation by the people on the inside, the public employee groups, and the public in the decision-making process, these kinds of problems are going to continue.

The other thing that has to do with public employee groups is, in other states, they are working out arrangements so that-- I don't think that living in institutions is good for the residents there, but also it is not a particularly pleasant thing to work in an institution. Other states have found ways to work with public employee groups so that employees can move right into the community with clients or work in collaboration with nonprofits. I think that that is something that really needs to be discussed. That might avoid some of the problems.

The final point we want to make is something-- When we find people, we ask for it and it hasn't happened and we are asking for it again. Our question is not whether Johnstone should be closed or not, but why only Johnstone? The entire history across the country is that institutions are just-- There are too many beds. Life in institutions is not good for people; it is not good for employees; and they are very, very expensive. I don't think we can avoid the fiscal problems we are facing today.

We called two years ago for a very open process to look at the entire system of Human Services, whether it is in Mental Health or Developmental Disabilities or Children's Services. Bring in the unions; bring in the Legislature. You know, call hearings. Bring in the experts, bring in parents,

bring in citizens, and let's develop, once and for all, a master plan that everybody can agree upon about where we are going with this issue, as opposed to every time we do something, it comes up in a vacuum and you have to call a hearing like this.

So, we are reiterating our call through a partnership model with the executive branch, the Legislature, parents, public employee unions, the nonprofit sector -- which we very much do believe in, and we don't appreciate the unions taking shots at the nonprofit sector any more than anyone should take a shot at the employee unions-- We think the time has come to throw the whole issue open in a thinking process, so we can avoid the kinds of problems we have had with this one.

The bottom line is, however, I think in terms of the testimony we have heard from the people who are living better lives in the community, that when all is said and done, the Johnstone decision is the correct one, and we support it.

Thank you.

ASSEMBLYMAN WATSON: Next will be Celia Feinstein. Celia Feinstein?

UNIDENTIFIED SPEAKER FROM AUDIENCE: She is not presently in the room.

ASSEMBLYMAN WATSON: She is not in the room. Okay, thank you. Dr. Kevin Walsh?

D R. K E V I N W A L S H: Good afternoon.

ASSEMBLYMAN WATSON: Good afternoon, Doctor. Please state your name for the record.

DR. WALSH: My name is Kevin Walsh. I am the Chairperson of the American Association on Mental Retardation, the Mideastern Region; that's Region 9. I live in New Jersey. I am not quite as sure of my position as most of the other people who have spoken today, but what I am sure of is that I would like to tell you a little bit about it, though.

I have worked, for almost 20 years, inside of various institutions, up until this year, and I have become very familiar with the positions of those who would close institutions and the positions of those who would have them stay open. I spent a lot of time studying about that and learning exactly what those positions are. I understand the reasoning that goes into them. I understand, I think, the emotion that goes into them, having helped parents put people into institutions, having helped families take people out of institutions, and having helped people themselves to get out of institutions. I believe I understand the emotions associated with that and something about the many positions as representative of certain organizations, which have been discussed today, and I don't have to go into.

On the other hand, as the father of four children, and a developmental psychologist, I believe I can empathize with some of those fears expressed by parents, and those expressed by people themselves who want to control their own lives. I know what that means, because I have sat across the table and helped people in that planning.

Based on these experiences, I have spoken and written a fair amount on the role and future of institutions. In this work I have actually often been rather critical of rapid and wholesale dismantling of institutions. I have argued against the adoption of strong anti-institutional positions, especially if they were -- or if I saw them as denigrating specialized services. Because of such positions, I think many of my colleagues in the community services sector have chided me, over the last couple of years especially, that I have been far too pro institution.

I say all this because I would like the Committee to understand some background to the fact that I sit here before you today and would like to speak in favor of closing Johnstone, despite some of those positions that I have espoused

in other forums. In my view, both of the positions that we have heard today -- the very strident positions both for and against the closure of institutions and for and against community service options -- to me, in some sense, overstate, perhaps, and potentially misrepresent a number of the issues. A few people got close to what seems to be the real issue, which is quality of life. We need to spend more time understanding what that is.

Institutions are not inherently good and they are not inherently bad, nor are community services inherently good or inherently bad. We seem to have missed that point. Human rights violations and abuses can occur, and have been reported, in both settings. Both settings are components of bureaucracies, and in both settings there is administration and there is labor. In both settings there are strengths and there are weaknesses. They are both susceptible to the unpleasant effects of organizations that are made up of human beings. Asking which of these settings is better, I think, begs the question sometimes and ignores the complexity of the problem.

Simply put, families -- a number of whom we have heard from today -- of people who are institutionalized, want some sense of security that their family member won't get lost in the shuffle; and further, that they will be safe and happy. That is what they are telling you. The community advocates, on the other hand, want people with developmental disabilities to be free and to live as normal a life -- and I want to stress that word, "normal" -- as possible. How can a reasonable person disagree with either of those positions? It is hard to understand how those two things can be fighting against each other.

What I think our challenge is together -- I think the last speaker alluded to this, and I would reinforce that-- Our challenge together is how to decide what our services will look

like into the future, and what are the principles that undergird those services? I have a few points in closing that I would like to say that I think go into that.

First, even if institutions are appropriate for certain groups of people -- and I am not convinced that they are not -- New Jersey has far too much institutional capacity at present. Second, the principle of normalization has been widely adopted in the field of developmental disabilities as a principle to basis for providing services. For many people in this State that is still somewhat of an unfulfilled promise.

As an aside, let me note that services should be based on principles. That is important. After a bit of bashing today, I would like to say that I applaud Dr. Nicholas in his work to develop a set of principles to guide a division. That is vitally important.

Third, even a conservative position on institutional closure suggests that New Jersey is behind in the process. This was also alluded to in earlier testimony. We cannot be so conservative that we are inert.

Fourth, to the extent that institutions are maintained at current levels, growth and community systems and other service network development -- and that is important -- such as regional centers, service networks, etc., are hampered.

And finally, but perhaps the most important point, is that many people with retardation and developmental disabilities want to receive more normalized services, and they are telling us that. The work of the Developmental Disabilities Council, and the work of the self-advocacy groups, is probably familiar to you, but I direct you in that regard there.

There are real concerns in the move from institutionally-based services to community-based services. That, in large part, is what my work has been pointing me to. But we need to do it; we need to get there. New Jersey needs to get there, because we are behind.

I think, from my view, that it is a reasonable first step in New Jersey to close Johnstone. I think the Division has been moving in that way. I think there are honorable intentions there. I don't think anybody is the bad guy here. There is too much divisiveness. If we can get together and work and proceed, making very sure that the needs of all the people in this -- the people who live at Johnstone, the families, the workers, and all of us -- are taken into account, that will be the best solution for everybody.

In my role as Chairperson of the AAMR in Region 9, I would like to support the State AAMR Chapter. I have spoken to the State Chapter Leader and I have reviewed all of the position papers of the National AAMR since 1976. None of them are in conflict with any of the testimony I have given today. I would like to say that the Region supports the State in its efforts to -- supports its perspective on the closing of Johnstone, which is that it is probably a good time to do that.

Thank you.

ASSEMBLYMAN WATSON: Thank you. Doctor, just before you get up, I would like to ask you a question. I have some concern. I want to be fair; I want to be fair with both sides. I want to be able to get the kind of evaluation we feel we could make some decisions on, and some recommendations.

I understand and I respect your testimony here today. My concern is that the placements -- and I am not, as I said before, against placing our clients in proper settings-- My concern is the trust to make intelligent decisions and recommendations through all of this transcribed testimony we have had today.

Those who are being placed outside of Johnstone now-- I would like to know whether they are getting the same level of service, or better service. I would like to know whether they are adjusting to the new environment. I would like to know

whether they are being placed close to their families in some way. And, I would like to have some evaluation of the clients who are being placed.

For us to take the kind of testimony that we are transcribing here today, we are not really getting at the bottom of this because we, as a Committee, cannot reach out for the parents, to find out from each individual parent how that child is doing or how they feel about that child; and also, to get back to the administration to see if the proper care is there, even at the level that they received when they were in Johnstone.

Can you give me some idea of how this Committee could, in a responsible way, find out the kind of information that I have just asked for, to be able to sit down and make a fair decision based upon--

DR. WALSH: I think that is a very reasonable, rational, and real appropriate need, and you need to fulfill that. Second, I think that kind of component has very much been done in other states that have closed developmental centers. That technology, in a sense, is there.

One other point is, I know there is a project -- correct me if I am wrong -- to have some evaluation of that process being researched, doing problematic evaluative research of that closure process by a contracted set of researchers. I think that needs to be made available, too.

I also think there is technology available that plenty of people who have been in and out of this room today have in terms of what program evaluation is; how you go about doing program evaluation in the real world, getting at parents' feelings, consumers' feelings, professionals' feelings, and staffs' feelings, assessing the quality of life. There are technologies for that which I am sure can be brought to bear on that population. There will be people, I would be willing to

venture to say, who would almost volunteer to do some of that work, if it is not too much, you know, to look at what that looks like.

So, I guess in response to your question, there is technology that will make that available to you -- program evaluation research technology. There is at least some component of that already underway, I believe, and I think that would solve, sir, a lot of the concerns you have about evaluating that. And I think the Division has to be aware of that, and also vitally interested in how that goes.

I guess finally, I think it should be shared publicly -- the outcome, the studies, the data. We ought not to lock that away in file drawers and computer disks, but we ought to get it out to people.

ASSEMBLYMAN WATSON: Are you compiling that kind of information, Commissioner Nicholas?

MS. FRASER: (speaking from audience) Mr. Watson, I want to just--

ASSEMBLYMAN WATSON: Wait a minute.

MS. FRASER: Oh, I'm sorry.

ASSEMBLYMAN WATSON: I am asking your Commissioner first. If he wants you to speak, then he can--

DR. NICHOLAS: That's fine. Actually, the Developmental Disabilities Council has a contract with Conroy and Feinstein. Celia Feinstein was the person who was supposed to be here to testify, it is my understanding, about what that process is. But that is being paid for by public dollars, and certainly would be public information. I think the Committee ought to be provided with the ongoing information which is being collected through that process.

ASSEMBLYMAN WATSON: How was that committee formed, in what way?

DR. NICHOLAS: It is not a committee. It is a consulting firm that is under contract to do specific evaluations of the placement of the Johnstone residents.

ASSEMBLYMAN WATSON: Then I am going to request that the information that is being given to you -- that the same information be given to this Committee.

DR. NICHOLAS: Absolutely.

ASSEMBLYMAN WATSON: Thank you.

DR. WALSH: I might add that Conroy and Feinstein, as a research entity, came about because of the Pennhurst dispersal in Pennsylvania -- following that thing. They did precisely the same kind of program evaluation study on the Pennhurst dispersal, and have become rather expert, or rather noted in that field. So we have some good people who are doing that.

ASSEMBLYMAN WATSON: Thank you, Doctor.

DR. WALSH: Thank you.

ASSEMBLYMAN WATSON: Commissioner -- or, Director--

DR. NICHOLAS: Yes?

ASSEMBLYMAN WATSON: The information you are getting from your consultants-- How fast are you getting that information?

DR. NICHOLAS: They are working, at this point, doing the actual on-site reviews of the client placements, so I have not gotten the results of--

ASSEMBLYMAN WATSON: Are they given to you as they review-- Are they giving you the information--

DR. NICHOLAS: Correct. We have been meeting with them on a monthly basis to get their follow-up. Their written reports we do not have yet, but when we get them we will be happy to share them with you.

ASSEMBLYMAN WATSON: Well, I would like to have them in plenty of time -- before the month of February.

DR. NICHOLAS: Okay. I will see what we can-- They are under contract to the DD Council, not to the Division, so it is external reviews of these placements. So, I will--

MS. FRASER: (speaking from audience) The first report from Conroy and Feinstein is to be in our office by the last week of December.

ASSEMBLYMAN WATSON: May we have a copy of your first report?

DR. NICHOLAS: Yes, you may.

ASSEMBLYMAN WATSON: We appreciate it. Thank you.

MS. FRASER: Mr. Watson, might I just--

ASSEMBLYMAN WATSON: Yes, sure.

MS. FRASER: (speaking from audience) I just wanted to comment. The reason that that contract was cut with those consultants was to assure exactly what your Committee is looking for. Our intention all along was to share with whomever wished to see it. We would be happy to come and make a presentation for you, or whenever.

ASSEMBLYMAN WATSON: Thank you. I am glad to hear that. But we would not have known your intentions, along with the information that you provided to us that this was being done--

MS. FRASER: (speaking from audience) We did-- In June we told you.

ASSEMBLYMAN WATSON: I don't recall. Do you recall that? (speaking to unidentified person) I don't recall that. I'm sorry. You may have, but I don't recall it. All right, thank you.

Mr. Topper -- Howard Topper?

H O W A R D T O P P E R: Honorable Chairman, honorable members of the Appropriations Committee, ladies and gentlemen--

ASSEMBLYMAN WATSON: Mr. Topper, would you please state your name?

MR. TOPPER: Yes. My name is Howard Topper. I have another parent with me, Darlene Dennis. I speak to you as a parent, as well as on behalf of Friends of Johnstone. I asked myself, what can I say today that you have not heard or read

before? What would make an impact with your Committee to keep Johnstone Research and Training Center intact? The facts speak for themselves.

My son is on the list for a group home. We, as well as many other parents here, are residents of Bergen County. We have been told there are no group home placements available in our area now, nor in the foreseeable future. Human Resources is playing a shuffling game with our children, just like three card monte. They are moving clients from one institution into other larger institutions.

We are now being asked to move our son back to the very developmental center he was in eight years ago. Tell me, is that progress? Johnstone is the smallest center, with less than 220 residents and a wonderful caring staff. The adjacent community of Bordentown welcomes them. There are over 4000 clients waiting at home for placement. Furthermore, there are 700 clients who are sent out-of-state to accommodate their needs. Why not bring them back to New Jersey and utilize the Johnstone facility? This would save the State a considerable amount of money, which then could be used to build more community-based homes and contribute to the Governor's overall plan of reducing State costs.

We have heard testimony today of the wonderful progress of disabled people allowed to leave institutions. We do not oppose this; we applaud it. But again, our children are being sacrificed. There are no community placements for most of the clients of Johnstone.

In closing, Friends of Johnstone takes offense to Frank Nardi's statement that today's meeting was generated by concern for the displacement of unionized staff, rather than the welfare of the residents of Johnstone. The love and concern the staff has shown to our children proved to us that it is much more than just a job to them.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Mr. Topper.

D A R L E N E D E N N I S: My name is Darlene Dennis. Good afternoon.

ASSEMBLYMAN WATSON: Good afternoon, Darlene.

MS. DENNIS: I am a parent. My son is (name deleted). He is 19 years old, and he is a Johnstone resident. His target date for leaving is December 18, next Wednesday. His destination is the North Jersey Developmental Center in Totowa.

When I visited this facility, my reaction was, number one, the cottage we were shown was very impressive, but we had no way of knowing if the other cottages looked as well, which is a concern. If our child must be moved to another cottage because he does not fit the program in the present cottage, then we, as parents, would like to believe that the new cottage is just as impressive as the cottage our child must leave.

Number two, another reaction was that, after seeing the upgraded cottage at Totowa, when we were shown other buildings, I got the feeling that everything was very old. Although clean and shiny, all those buildings needed upgrading. Those same facilities at Johnstone look more updated and sturdy. Some of the facilities were the school, the gym, and the vocational rehab building. It didn't seem that they had enough recreational equipment for the gym, or vocational equipment and materials, and the place just really looked in need.

Number three, I felt my son had room made for him to squeeze into what was already established, rather than being placed in a program that was ready to receive him.

Number four, some of the planning is based on trial and error. "We will see if this works. If not, we will try something different." But no real alternative plans seem to be in place. For example, my son has problems controlling his sexual feelings. When he is aroused, he has a tendency to

masturbate wherever he is. Well, he is being placed in a cottage with schizophrenic women who are older. These types of women also have a tendency to be highly sexed, violent, and abusive. My son does not display his sexual behavior in a problematic way at the cottage in Johnstone because he lives with all men. But at school, where there are female teachers, female students, and other females, he displays his sexual behavior more often.

I feel that if (name deleted) is placed in this environment, the sweet, kind, considerate staff people at the North Jersey Developmental Center -- because they are really, really sweet people -- are going to have a serious case of hell breaking loose in their facility. Therefore, I would like to propose an alternate plan for my son.

Rather than have him go through that situation in Totowa, I would like to set up a pilot program in the community that would include my son, (name deleted), (name deleted) -- he is another resident at Johnstone -- and (name deleted), whose mother is (name deleted). He is a community resident with special needs recently returned from out-of-state placement. They are not community ready, so this program would focus on helping to prepare them for the community. This pilot project would address the residents' developmental and emotional needs. Written into the plan would be a behavior modification program to address the acting out behavior that these residents are known to display.

This would be a unique program because: Number one, it would address two--

ASSEMBLYMAN WATSON: Darlene?

MS. DENNIS: Yes?

ASSEMBLYMAN WATSON: Just for the record -- and I hate to interrupt you-- The Chair is going to request that those names be restricted from the testimony. Would you please refrain from naming the names?

MS. DENNIS: Oh, okay. Yes, I will. Number one, it would address two different needs to additionally address two different agencies, those being developmental disabilities and emotional problems served by DDD and DMH respectively. It would be a good mix, because, number two, all three residents are 19, 19, and 20 years old. Number three, all three residents are in the aging out category, and will soon be out of school.

Number four, this pilot project could be used as a model program for future community programs that must be developed to assist in addressing the housing needs of other residents being moved back into the community with similar problems.

Number five, these residents represent a group of extremely difficult youths to locate placement for. Therefore, they usually take a backseat to easier-to-place youths, which is why Johnstone was such a unique placement for many of New Jersey's extra special needs residents.

Number six, at this time, no one is trying to address this aspect of the problem, because everyone is so busy just trying to locate housing and struggling to find a program to match where the housing is located to suit the needs of the resident.

Number seven, I have already been told by DDD Special Needs and New Community Projects person, Goldie Ellis, that DDD won't be developing any of its special needs housing for another year or so.

Number eight, my son can't afford to wait a whole year or so. When my son was in New Lisbon, which was the wrong placement for him, he got so out of hand they were constantly shooting him up with drugs. When I would visit him, he would look like a zombie. I don't want my child to go through that again. He doesn't deserve that.

Number nine, the other two young men-- Why shouldn't they all be allowed the right to a pioneer program set up to address their needs and community based for easy access to families and other community supports, as well as being a more normal way of living?

Number 10, having only three residents in an apartment would allow them to live in a building that is not labeled "institutional housing." It doesn't even have to be called a "group home." This would also fit the normalization process for people to live in an environment as normal as possible.

Number 11, we would like to set this housing up so that our residents would have the option to buy at a future date. We plan to work with AAMH in Elizabeth. Sid Blanchard and Marshall Board will be our consultants for technical assistance, instructing us how to use the credit -- the tax credits -- and other creative financing to allow our residents to become homeowners, future taxpayers, and contributing members to the society at large. No longer will they or their parents have to worry about them being uprooted, because they will be the owners of their own dwelling places.

As parents, we want to help our children, as well as the organizations we represent. Between us, we have numerous community contacts and plan to continue using local, county, and State resources to help enhance our program.

The organizations we represent are ETQ, Inc. -- Expanding Towards Quality -- and Community Services, Inc., which is a nonprofit, private organization with 501-C(3) status. I helped to found it with my mother and another colleague in 1984. We started out trying to set up housing for children in need of residential placement. Eventually, we became a referral and resource entity for residents needing supportive community services and other supports. We have come full circle to again address the housing needs of this population. This time we have the technical assistance and

expertise of established housing program directors Alex Guielion (phonetic spelling) of Spectrum for Living, and Sid Blanchard of AAMH in Elizabeth. DCA and HUD will also be a part of the resource piece to help with the financial part of the plan.

The housing that Sid Blanchard set up is located in the community in two-family or multi-unit dwellings, and residents' housing is mixed in with the general population. Our residents will be provided with supportive services, 24-hour supervision, and case management from community agencies.

The Friends of Johnstone-- Through this organization, we would like to establish veteran type housing for Johnstone residents based on a model run by Al Skilione (phonetic spelling) in Bergen County, which looks more like a country club or resort than an institution, having supportive services on grounds, as well as off grounds. It has incorporated itself to become a viable part of the community where it is located.

The Statewide Parents' Association for the Children's Efforts -- SPACE -- is our liaison organization connecting us with parents and parents' support groups throughout the State of New Jersey. This organization, in the past, served parents primarily of children with mental health problems. But recently it has attracted parents with children having both mental health and developmental disabilities. In the future, we would like to address the housing needs of the community residents sitting on a five-year waiting list. Through SPACE, we plan to receive our community referrals. All three parents are working with other parents in the organizations we are representing.

There is one other thing I wanted to make note of. Where is the money coming from to establish this new program? Well, the money could come from the Department of Research, Program Development, DDD, DMH, DYFS, or any other area where

there is a hidden emergency fund in the State, because the way the Johnstone residents are being uprooted from their homes is truly presenting an emergency state of affairs.

This is the holiday season, and people are being taken away from friends, not even being allowed to spend a last Christmas together. Parents are feeling rushed and pushed into making quick decisions based on State deadlines. It just feels as though there is no compassion for parents, residents, or friends. A computer put the plan together, and left the human element of compassion out.

Before closing, I would like to add that this closing of Johnstone issue is not an issue of institution versus community. Most of us parents do not feel like that. We want what is best for the residents. If they are community ready and an adequate program is available for them out there, then, hey, go for it. But if the community has not yet been able to establish itself to serve the particular needs that are addressed in institutions, then allow the resident to receive what will best serve his or her needs.

So, please, let us not fight one another, but join hands and all of us fight and work together to get the needs of our loved ones served appropriately in a positive way.

Thank you for your time.

ASSEMBLYMAN WATSON: Thank you for your testimony, Ms. Dennis, and also Mr. Topper, thank you for your testimony.

Next will be Jim Conoy. (indiscernible comment) Is it Conroy then?

UNIDENTIFIED SPEAKER FROM AUDIENCE: He is not here.

ASSEMBLYMAN WATSON: Okay. Patricia Shillingburg?

P A T R I C I A S H I L L I N G B U R G: Thank you. My name is Patricia Shillingburg, and I represent myself. You have my written testimony. I will have a few diversions from time to time, having heard various things today, though I don't want to go over the whole story of everything you have heard.

I welcome this opportunity to testify before you today on the subject of the closure of the Johnstone Research and Training Center.

I have been involved in affairs dealing with people who are mentally retarded for approximately 20 years. I served on the Board of Trustees at what is now called the North Princeton Developmental Center for three years and on the State Board of Human Services for eight, being appointed by both Governors Byrne and Kean. Eleven years ago, I founded an organization called Our House, Inc., which today provides residential programs in the community for nearly 50 people, as well as employment support services.

I started my house because I have a daughter, (name deleted), who is 22 years old and is severely mentally retarded. She lives now, presently, in an Our House, Inc. group home and benefits from its employment program. My daughter's IQ is about 30. She operates on the intellectual level of a two-and-a-half year old. She is nonverbal; she has no academic skills. She can't count money. She has cerebral palsy and she has some acting out behavioral problems which have improved with age, but include never having slept through the night and needing supervision 24 hours a day.

From the ages of seven to fourteen, she lived in an institution, so I am intimately familiar with the differences in the quality of life in each environment. I also have, over the years, visited all of the State institutions for both the mentally retarded and the mentally ill, and I visited Johnstone several times. What I remember most about Johnstone is the dust and the stench.

I would also like to divert for a moment and discuss some of the language I have heard today. I have heard people refer to people who are in institutions for the mentally retarded as patients, children, students. They are none of those things. They are human beings who have a right to

dignity and to be called what they are as individuals. People who are not ill are not patients. People who are over 21 and, in many instances, over 18, are not children, and people who are not in school are not students.

I think that what is most important in providing services for people with mental retardation is that those services be in the best interest of those we are serving, and only those we are serving. Fifty years ago the best we had to offer as a society was institutions. Today, institutions are known not to be the best. As we enter the year 2000, we know to help any person to reach his highest potential, he requires integration into society, not segregation; freedom of expression and action, not repression; and independence in all things he can do for himself, not dependence on others. Life in the community offers integration, freedom, and independence. Life in an institution offers only segregation, repression, and dependence.

I would like to give a few examples to explain what I think of as the difference: My daughter, (name deleted), has traveled with others living in the community to interesting places far away from New Jersey. She goes horseback riding and swimming at the Y. She works at the Pathmark collecting carts. She has her own room and watches on her own TV whatever she chooses to watch. She has what is called a McCaw, which is a language board where she can push buttons and it speaks, but someone has to pay attention to make sure that that is working.

Because she selects the menu and prepares the meal, with assistance, one week in six at her group home, she can express her independence in what she cooks and eats. My daughter's life is integrated in the community at large. She works; she has freedom to choose how she spends her leisure time; and she has opportunity to be as independent as she is capable of being.

If (name deleted) lived in an institution, she would not have traveled very far beyond its gates, certainly not around the country. She would have limited work opportunities. She would live in a room with several people, and would probably only watch on TV what the staff had on in the day room. She would never have access to a kitchen or to the foods she really liked. She would be segregated from the community, repressed from doing what she enjoyed most, and would be, in all things, dependent.

My daughter's story is no different from the thousands of others who have moved from institutions and prospered. None of my friends who have moved from institutions would choose to return. They describe institutions with words like -- and you have heard some of them today -- prison, jail, hell. In fact, the goal of most in group homes is to move into their own apartments.

I have also heard discussion today about the issue of readiness. Was so and so ready to move into the community? To move into the community, readiness is not an issue. Institutions are not like high schools, preparing students for college. The only preparation for the community is the community itself. My daughter, and many others like her, have proven that.

My final point is that New Jersey institutionalizes a larger percentage of its population which is mentally retarded than any other state in the Union, except for Wyoming. New Jersey institutionalizes 7% of its mentally retarded population. Wyoming institutionalizes 9%; California 2%; New York 2%; Texas 2%. Once a progressive State in the area of mental retardation, our State is now considered light years behind the majority of states in this field. It is well-known that the future lies not in institutions, but in the community. Proof of this lies in the fact that the vast majority of parents today are seeking community residential

placements for their children. That is why the waiting list for community placements in New Jersey is over 3500 people, and the waiting list for institutions is only 103.

There are parents today who believe that institutions are the only answer for their children, but these are, on the whole, parents who bought into the system when there was no other alternative and, remember, there was no other alternative 15 years ago. There has only been an alternative since the early '80s. The change in philosophy frightens them, and I understand their fear. Change is very, very difficult and very stressful. Even when a typical family makes a move from one house to another, it takes about a year for everybody to adjust, so it takes a year to adjust to a move for anybody.

But the new generation of parents, those whose children have always lived at home and have been educated through the public school system, which we have been doing in New Jersey since the mid-'50s-- These parents know that their children can function in the community, because they already have for 40 or 50 years.

The closure of Johnstone Research and Training Center is appropriate and inevitable, just as it is inevitable that all institutions for people with mental retardation will close down eventually. First, they are not good places for people to live, and the second reason is because nobody is going to buy into them and they will just dissolve with history.

Johnstone is a vestige of the past, and an anachronism for the future.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Ms. Shillingburg. Next will be John Randolph.

J O H N R A N D O L P H: Good afternoon.

ASSEMBLYMAN WATSON: Good afternoon. Would you please state your name for the record?

MR. RANDOLPH: My name is John Randolph. I am associated with the Mercer HOPE Association for the Self-Advocacy Project. During my time, I was 46 years in institutions, from 1937 to 1981. From then, in 1981, I was moved into the community, and lived in a supervised apartment for three years under the Skilled Training by Mercer ARC. Then from there, 1985, I was released under the program to be independent. I live in a senior citizen high rise right here in Trenton. I worked at a State sales office for four years, and now I am retired and am living more freely.

Since then, I am glad to see that the Johnstone institution is being closed and is being used for other purposes. We are known as the largest organization in the self-advocacy movement in the world. We now have 16 units, and we are one of the number one top in the nation. That is one of the reasons why it is good to see the Johnstone people being moved into the community to get involved with the self-advocacy movement. We have one group called HOPE -- known as Helping Other People Everywhere -- here in Mercer County.

During my eight years with the self-advocacy movement-- I started as an apprentice for the State of New Jersey for four years. Now we have a union board known as New Jersey United Self Advocate. We have 36 resident people on the board. From that, we also have a committee known as the Consumers Advisory Board, and I am the President of that, under the Division of Licenses and Inspection of DDD.

From that, I have been President for four years with the New Jersey (indiscernible), a year with the Consumers Advisory Board, and now -- and also a President for the NJUSA. I now am Treasurer of the New Jersey Association and also Sergeant at Arms for the Handicapped HOPE. From that, that gave me the thrill to be able to speak in front of this Committee, as my first experience.

My first experience was eight years ago when I was chosen by the Mercer ARC to represent the Association of Retarded Citizens in Nairobi, Kenya at the 8th Congress, known as International League Society for Persons Mentally Handicapped. That was my great thrill, to speak in front of the 100 people on the community, then finally speaking in front of 500 people of 15 different languages. No one ever expected a person institutionalized since '81, to be selected in '82 to go with a group known as the Bancroft Group down in South Jersey, to go to a strange country to speak in his own language in front of a group of people who had never heard about disabled associations.

So from that, it gave me a great thrill to state my testimony, like I am doing today, and also my testimony at Washington for the group known as the Community (indiscernible). They presented the money back to the program to get more people out of institutions to be able to be independent in the community.

I wish, in God's name and trust, that this Committee will be able to improve my testimony to get more people out of institutions into the community, and also into self-advocacy projects which are now a big hand for the disabled.

I thank you.

ASSEMBLYMAN WATSON: Thank you, Mr. Randolph. Thank you for your testimony.

We will now have Kate Blizard. Good afternoon.

K A T E B L I Z A R D: Good afternoon.

ASSEMBLYMAN WATSON: Would you please state your name for the record?

MS. BLIZARD: Kate Blizard. I am an advocate with United Cerebral Palsy of New Jersey. I know John is a hard act to follow. John said a lot of what I was going to say, probably better than what I can say it, and considering the hour of the day, I will try to say what I think is important for the Committee members to hear.

I'll say first that UCPNJ welcomes the opportunity and appreciates the time given us to speak about the closing. UCPNJ fully supports the closing of Johnstone, and stands ready to assist persons leaving Johnstone.

What I would like to say is, as an advocate, I have been working with those with developmental disabilities in developmental centers since about 1987. During this time, I have had the opportunity to meet and become friends with many, many people called developmentally disabled, with many different levels of disabilities, and many different backgrounds.

I have been here all day. Many, many wise things have been said. What I can probably contribute is that I notice that unfortunately there was not a voice of a person who presently lives at Johnstone. One of the things that I do is to assist persons -- establish what we call support and advocacy groups. UCP, in cooperation with ARC, decided maybe about a year ago to try to go into Johnstone and to establish some advocacy groups -- activities to introduce advocacy skills that people would need as they were transitioning into community living and into other developmental centers.

So we have been doing that together for about the past year. There are approximately four or five groups throughout Johnstone where we meet on either a monthly or twice monthly basis. We bring in experts on community living, on relationships, and on employment. We invite them to come to speak to the smaller groups of people. All of our groups have staff liaisons. We are working with the administration at Johnstone, as well as with the residents and staff. We think it is important for the staff to be included in what people are being told about community living, what they need to know to live outside, what they need to advocate for themselves, so we try to incorporate the staff at Johnstone into this.

In the past month, we have worked with both severely physically and cognitively disabled persons. That includes speech impaired persons, deaf persons, and then we worked also with those who are marginally mentally retarded at Johnstone.

I think it is important to understand that we enter these institutions not to win disciples. We go in to assist persons in achieving self-expression, self-determination, empowerment. This can be done, yes, even for the most severely disabled among us. It can be done. I have seen it done. I have been fortunate enough to be part of it. We leave our personal views at the front door of Johnstone. We are there to listen. We are there to ask what people need. We attempt to assist them in achieving it.

We respect those we serve. We care too much for the lives and souls of the people we serve at Johnstone to do anything else. In our groups at Johnstone, we have our own discussions and hearings. We have talked about the closing of Johnstone. Many people have talked about being happy to leave. Other people have expressed displeasure and anger. When we talked more about it and we listened to people and what they were really saying, we found that a lot of that anger about not wanting to leave Johnstone was because they have not been told fully what everything is about; what they are to expect, what is going to happen to them. There is a lot of fear of the unknown. There is concern for the friends they have. The less physically disabled, the less mentally disabled have real concerns about their friends there who are more disabled.

We go in there to explain what is going on. I don't go in there to program, to try to shift somebody from one side to the other. My job is to deliver factual information. I explain the options. We answer the questions clearly and honestly. Then we have found out, in these small groups, that when people understand more of what is going on -- and I want

to reinforce that I am talking about working with people with multiple handicaps, not just what we call marginally mentally retarded people-- Across-the-board, we have worked in all of the cottages where we have groups. But when people start to understand what the process is, they still say, "Yes, I am afraid. Yes, I enjoy the staff here. They are my friends." But when we talk more and more about it, they still-- Most of them come out and say, "But I am willing to take the chance and leave, now that I understand more about what is going on."

When I reassure people that no one will be abandoned, that everyone's needs will be addressed, that all voices will be heard, I know that I am telling the truth. My respected colleagues from ARC and I are committed to helping people leaving Johnstone link up with self-help groups in the community and in other centers. We are planning to help people to know where to go if they want to join another support group or advocacy group, or if they are going to a particular community, if we know there are self-advocates living in those communities, so they do have a link; they have someone they can call and talk to; or, even in the developmental centers where we have self-advocacy groups. We couldn't -- I and my colleagues from ARC-- We would not do this work if we didn't truly believe that ARC and UCP hold the same sense of commitment to assist, in any way possible, with the transition of the people now living at Johnstone.

Just one quick personal reflection, if I may. You have been listening to a person sitting here who in 1950 was destined for institutional living. It was only a twist of fate that my mother took me home, and kept me at home even after my mother gave birth to my sister with Down's syndrome 10 years later. I have learned a lot about our developmental centers over these past years, and I have come to understand the families of these people we serve. I have been caught in the cross fire. I have felt their tears. I have seen people

struggling to adjust to living "on the outside." I have become friends with those learning and living on the outside. I have watched my own sister dare to live on the outside.

When all is said and done, I truly believe it is the better way. Thank you.

ASSEMBLYMAN WATSON: Thank you, Ms. Blizard.

Is there a Cindy Polvich in the room? (no response) Anthony Brown? Good afternoon.

A N T H O N Y B R O W N: Good afternoon.

ASSEMBLYMAN WATSON: Please state your name for the record, Tony.

MR. BROWN: My name is Tony Brown. I am from the Middlesex County Raritan Valley Unit, and I am in support of living. I was in Johnstone for five years, and now I am out here for about going on four years. When I was at Johnstone, I noticed a lot of things. I had my ups and downs. You know, I tried to cope with my problems. I had a different kind of problem, but I have seen other students have their own problems.

I grew up. Learning in there is growing up to live and move on. I talked to a certain person in that place, a psychologist. He isn't there anymore, but he told me the one thing is to just do it. I looked at myself and I said, "The only way, if I have to do it, is to talk to myself." I moved on from one cottage to another. I saw a lot of things from Rice Hall to Gregory Hall. What I did was help other students learn what it is about to move from an institution. If they want to move or stay there, that is their choice. I didn't make that decision.

I had a lot of friends who have now moved out. You know, they listened to me, because I go down there about once a month and try to talk to them. Some of them say, "Well, how is it out there while you are out there?" I say, "Well, it's good. Don't you give up. You might make it." Now I have a few of them who are out here. One guy talked about-- I want

to bring him to White Horse Circle. He was a close friend of mine. He had problems. He came from another place. He came to Johnstone, and he didn't know what it was about. I came to Johnstone, and I didn't know what it was about. We went through it and we got it over with.

Now they have decided to close Johnstone, since I left. Things when I was there were just about the same, but things have changed since I left. No spending money for other students. It went down from about maybe $5 to $3. If they get to go on trips, that would be cut out. If they go to, like, a deli on campus, that would be cut down to maybe once a week, instead of two times a week. They would be more restricted because they didn't have the money.

But I say to that, you know, most people there like the place no matter what. I mean, if you try to force them to come out, that is their decision, you know. They have their rights. These parents here, you know, they are fighting for the place to stay open. I have seen a lot of things here in the State of New Jersey, what they are doing here, just putting up other buildings, you know, with the money, and stuff like that, and putting a highway behind Johnstone, which it never went through, but now it is going through. The bridge has been there behind Johnstone at East Burlington Street for 20 years, before I was born. But now they want it to go through, and I think it is a waste of time.

I think all these activities go on. The kids really miss-- If they go to another institution, they might think to themselves, like, I was a special person to them, like a big brother. I used to always go down there and talk to them, or talk to them on the phone. I get what they are saying to me, you know. They get the word out. I say, "Well, you just keep it up. I will come down and see you. Don't give up hope because I have left there, because you will get the chance someday if you want it."

It is just a shame. I hate to see it closed, because, you know, to me, it was decent. Some students didn't like the staff. I tried to talk to some students who had that problem with the staff. I grew out of my own problems. I try to tell them, you can grow out, you can do a lot of things. Some students listen. Now they are going to other institutions, so how can I talk to them, because they are all scattered all over the place?

ASSEMBLYMAN WATSON: Well, it's nice that you go back to the institution to try to help others.

MR. BROWN: Oh, yeah, definitely. I go down there and I check on it, you know, and stuff. Oh, yes.

ASSEMBLYMAN WATSON: It's beautiful. I am quite sure that for someone who has been through it, to be able to go back and have discussions with the others, is helping the others, and I am proud to have you here this afternoon.

MR. BROWN: Yeah, exactly. You know, as I say, I have people where I am-- They have people who they brought into our program who share an apartment with us. There are, like, four -- two in each room. One came and lived with me, and then he wasn't even ready. It's like you get somebody leaving Johnstone, and you don't even know if they are ready. Maybe they are telling you that they want to stay there, because maybe they are not ready, you know.

ASSEMBLYMAN WATSON: Right. Well, thank you for your testimony this afternoon, sir.

MR. BROWN: Okay.

ASSEMBLYMAN WATSON: Lisa Zuckerman? (no response) Suzette Harmon?

S U Z E T T E H A R M O N: Good afternoon. My name is Suzette Harmon, and I am here today as the parent of an autistic child and as a member of the Board of Trustees for the New Jersey Center for Outreach Services for the Autism

Community, also commonly known as COSAC. I appreciate the opportunity to share my views and perspectives on the closing of the Johnstone Center.

First I would like to tell you a little bit about my son, (name deleted). My oldest child, at nine-and-a-half years of age, is extremely healthy, but he is autistic. Looking at a photo, anyone would agree, I'm sure, that he is a handsome, very normal-looking boy. He loves sports. He bowls, swims, plays t-ball, and has even made eight out of ten foul shots in competition. We are even able to use upcoming high school football games as incentives and rewards for good behavior.

Even with all his positive attributes, he is quite the paradox. He has a wonderful sense of humor, but can't hold a conversation. He is a whiz at Nintendo games, but is unable to tie his own shoes. He taught himself to read before he used any functional language. He never showed even a remote interest in music as a young child, but last spring opened a school program by singing "The Star-Spangled Banner."

He is very lucky. He attends our local public school where two classes for autistic children are provided. His successes are due to the all-around efforts of those surrounding him -- his family, teachers, school district, and COSAC.

When he was born, of course we had hopes and dreams for him just as any other proud parent has for a child. When his autism was diagnosed, our hopes and dreams didn't disappear, but we slowly adjusted them. As the likelihood of his living independently or with family diminishes, my dreams for him do not include living in an institution.

I support the closure of Johnstone because I see it as a step in the right direction. With literally thousands of developmentally disabled people on a waiting list for community-based living, I believe New Jersey owes its most vulnerable citizens a chance at a more productive, more

normalized adult life. I want to see New Jersey place an emphasis, not on maintaining or improving institutions, but rather, investing in the community and in the future.

Of equal importance, however, is the involvement of families of people with disabling conditions and the persons who themselves have developmental disabilities in making decisions regarding any aspect of their lives. Finally, the change in placement should lead to a lasting improved quality of life for those residents being institutionalized.

My son has thrived in the public school setting which parallels community-based living in so many respects. He has unlimited opportunity to mingle with normal children and participate in many activities within the community.

For him to remain a part of the community, to someday hold a job, possibly have friends, and to be among normal, regular people on a day-to-day basis would be a dream come true.

Please give him the chance to become a better citizen and hopefully be able to give back to the community. Give every developmentally disabled person a chance at a more "normalized" adult life by providing adequate numbers of group homes.

Thank you.

ASSEMBLYMAN WATSON: Thank you, Ms. Harmon, and here is your handsome son.

MS. HARMON: Thank you.

ASSEMBLYMAN WATSON: That concludes the list I had before me today. Is there anyone else in the audience who has been waiting to testify, but didn't submit their name? (no response)

Seeing none, I just want to say the public hearing record will stay open until December 18 in order for you to send in any written information. Please send it to the Committee Aide, Michael Basarab, Office of Legislative

Services, CN 068, Trenton, New Jersey, 08625, or FAX to (609) 777-4606.

This hearing is adjourned.

(HEARING CONCLUDED)

APPENDIX

Assembly Appropriations Committee

Testimony of
Alan J. Gibbs, Commissioner
Department of Human Services

December 11, 1991

Mr. Chairman, the budget, as approved by the Governor, for State Fiscal Year 1992 provides for the phase out of the E. R. Johnstone Training and Research Center beginning July 1, 1991.

In my testimony this morning I would like to bring you up to date on where we are in implementing the plan to transfer clients either to more appropriate community settings or to other institutions with certified cottages and higher staffing levels, and our plan to provide other employment opportunities to all staff at Johnstone.

In May of this year we provided you with a plan for closure. Last month, we submitted an amended plan with more detailed information.

Mr. Chairman, you may be interested in knowing that we sought comment on this plan at a meeting of parents of Johnstone residents in October.

At that meeting—which we should have had long ago—we explained our plans to close Johnstone. We answered their questions and listened to their concerns. We held this meeting to ensure the best and smoothest transition possible. Our amended plan reflects some of their concerns.

We also shared with parents our projections for the transfer of Johnstone residents through April 1992.

To date, we have placed 51 Johnstone residents. Twenty-one of these residents have been relocated to community placements; 30 have been relocated to other institutions. We still have 177 residents at the facility.

We expect that by April we will have completed the placement of 126 clients.

The actual rate of placement depends on two factors: first, the readiness of facilities to which residents are assigned, and, second, the involvement of parents.

We make each transfer according to an Individual Habilitation Plan or IHP. Every placement has been made and will be made in accord with the needs and preferences outlined in the IHP and with parents fully involved.

We are committed to ensuring that every Johnstone resident receives a placement that's at least equal, and in most instances better, than their current placement at Johnstone.

Where this involves placement in another developmental center, that transfer will be into ICF/MR certified living units with higher staffing levels.

Where a community placement is appropriate, our community liaisons work with the Johnstone Center staff to develop transitional plans.

As I have said repeatedly, every Johnstone resident will be provided a placement that will be as good or better than his or her current placement.

We're very committed to this. That's why a nationally known research firm, Conroy and Feinstein, will assess the quality of life of Johnstone residents before and after they leave the center.

We won't make placements that offer any less. We will correct any situation where we find that a resident has a lesser quality of life in his or her new placement.

I believe that we have also made every effort to accommodate the staff at Johnstone. We have held to our commitment to provide other employment opportunities for staff who will be affected by the closure.

I have directed that vacancies at other Human Services facilities will not be filled until full consideration is given to Johnstone employees.

There are also employment opportunities available in the community service network. We conducted a survey of Johnstone employees to elicit their preferences for work locations.

We've arranged tours of the possible work locations and we have set up interviews as employees respond and as vacancies are posted.

We've allowed special shared job arrangements as the phase out proceeds to accommodate the operational needs of both the receiving facility and Johnstone.

To date, 46 staff have been separated from Johnstone since February 1991. We now have 262 regular employees on the payroll at the facility.

Many of these separations represent early retirement selected by employees, but they also include transfers to other facilities operated by the Division of Developmental Disabilities and the Division of Mental Health and Hospitals.

Mr. Chairman, I would now like to place the closing of Johnstone in a slightly larger context. For most of this century, we've held to the vision of Professor E. R. Johnstone, one of New Jersey's pioneers in providing services to children with developmental disabilities.

Johnstone's vision was one of an idyllic institution where children with developmental disabilities lived out their entire lives.

Today, those children and adults have new opportunities. We've changed and expanded the programs and services we offer them. We take special steps—as we have at Johnstone—to involve and support parents in planning for their loved ones.

Today, many of these children and adults can live alongside you or me as neighbors.

We have a different, brighter view that says that no matter how good it is, an institution isn't a home.

The idyllic institution Professor Johnstone created for children has lost its original luster and allure. Some institutions—like Johnstone—now offer a substandard level of care to some of the resident they serve.

We can do better.

We no longer see most of our clients staying in an institution for life. And yet, even when Johnstone closes, we will still be meeting the needs of more than 4,000 people in institutions.

People are no longer waiting to go into institutions; they're waiting to go into community services. Many of the 4,000 I mentioned are waiting to go into the community.

There's something I must make very clear. Whether or not we close Johnstone, the money for community placements is scarce. The money for the Johnstone community placements is coming from the Johnstone budget. It is the only way we can assure those residents a shot at a better life, a life in the community.

Closing non-certified beds in Johnstone and other institutions allows us to make additional community placements, over and above the number of beds we close, because the amount we spend on non-certified institutional beds is greater than what we spend on a community placement.

Unless and until we make and implement the hard decisions to close an institution like Johnstone, we will never have the financial resources to meet our community placement needs.

Mr. Chairman, at one time the demand was for institutions. Today, the demand is for supported living, independent living, supervised apartments, group homes, and skill development homes.

Other societal factors also affect demand. Our clients now live longer. The needs of new clients are expanding and shifting, because of the birth of babies who are addicted to drugs or who lack adequate prenatal care.

These are today's realities and I believe that we are addressing those realities.

Mr. Chairman, all of us who make policies or deliver services for those with developmental disabilities face an enormous challenge.

In meeting this challenge we have to answer many questions about where we're headed.

Are we headed toward a time when we provide families with reasonable supports and services—such as respite care and skill development—to allow a family member to live in the community?

Are we headed toward a time when most children and adults with severe disabilities will no longer have to endure institutions, custodial care, and separation from their families and communities?

Are we headed toward a time when we will limit the money we use to support buildings and places and practices that have remained virtually unchanged in design and intent for more than a century?

Mr. Chairman, I think we are headed toward that time. And the credit belongs to the families, the advocates, the legislators, the professionals and the public who have fought for the rights of those with disabilities.

But, most of all, the credit belongs to those with severe disabilities who challenge us to challenge them.

I am confident we will meet their challenge with a full range of support services, with the smallest possible institutions, with certified beds in these smaller institutions, with community placements made possible by redirecting funds from substandard cottages, with respite care and skill development.

With the Governor's support and with your continued help, Mr. Chairman, I am confident that we will continue to do what is right for our time and for those we serve.

CLOSING JOHNSTONE

WHY AND HOW

May 1, 1991

As Amended October 15, 1991

DRAFT

The New Jersey Department of Human Services
Division of Developmental Disabilities

Alan J. Gibbs, Commissioner

Robert B. Nicholas, Ph.D., Director

12X

On May 1, 1991, the Division of Developmental Disabilities submitted its plan to close the Johnstone Training and Research Center during fiscal year 1992 to the Senate and Assembly Appropriations Committees. The closure had been announced in the Governor's budget message in February.

The plan as submitted assumed that $5.2 million would be available to fund the cost of community placements.

When the 1992 Appropriation Act was passed, it permitted a longer period, two fiscal years, to close Johnstone and increased the level of funding available to complete the project. These changes in the fundamental assumptions underlying the plan necessitated this plan amendment.

Executive Summary

- Every year for the past thirteen years, the Division of Developmental Disabilities (DDD) has moved about 300 people with mental retardation from its institutions into the community.

- Today the Division serves over 18,000 people; more live in the community than live in institutions.

- The Division is committed to the principle that no institutional resident will be moved into the community without an appropriate placement and appropriate support services. This commitment will be completely upheld in the coming months at Johnstone.

- The Division is further committed to a guarantee that Johnstone residents will sustain or improve their current quality of life after the closing. If a study by an outside researcher finds that any former Johnstone resident has a worsened quality of life in his or her new placement, the Division will take immediate corrective action.

- The Division's long-term commitment to reducing the population of developmental centers has long been understood and accepted by advocates for people with disabilities and other governmental agencies involved with the Division's resource decisions.

13X

❑The Division's shift toward serving people with developmental disabilities in the community is part of a national trend in this direction. In 1977, the total expenditures of community services programs in the nation was $879 million. By 1988, total expenditures had reached $5.6 billion.

❑New Jersey is not in the lead in the movement to serve people with developmental disabilities in the community. In fact, only three other states have more people in institutions at this point--Texas, New York and California.

❑Many Johnstone residents are very good candidates for immediate community placement; others can benefit from the improved programming and physical environment provided in ICF/MR settings.

❑Only 40 of the residents at Johnstone live in units certified under Intermediate Care Facility for the Mentally Retarded (ICF/MR) standards.

❑A 1990 catalogue of the critical capital needs at Johnstone exceeded $12 million. A more recent estimate rose to $15 million--and this would merely make the facility habitable; it would not make it possible to certify additional beds under ICF/MR.

❑In the past, the Division has achieved community placements for developmental center residents who need them through a strategy of closing units of facilities not certified under ICF/MR.

❑Uncertified beds have declined from 2322 in 1978, to 1259 today.

❑The Division is working with each resident to be sure that the placement decision made reflects the resident's needs and individual preferences.

❑The Developmental Disabilities Council, in cooperation with the Division and the Association for Retarded Citizens/NJ, has initiated a self advocacy project that seeks to address the unique needs of the residents of Johnstone during the closure.

❑Personal interviews and case record reviews have confirmed that the people who live at Johnstone can be far better served in other settings.

14X

❑Placement plans have been developed for Johnstone residents that will meet the needs and preferences outlined in their individual habilitation plans. Where community placement has been identified as the appropriate service, community liaison staff are working with developmental center staff to develop transitional plans.

❑The people who will be transferred into other developmental centers will be moved into living units which are ICF/MR certified.

❑Recommendations for specific types of community homes have been made for some Johnstone residents and the matching process has begun. Transition plans are being developed for each of these individuals.

❑The Division fully endorses the program to support the families currently being developed by the Developmental Disabilities Council. This plan will include a toll-free hotline to answer questions and address concerns, parent support groups, assistance in learning how to participate effectively in Division planning for the resident and opportunities to network with parents of Division clients who live in a variety of living arrangements.

❑Additionally, staff from the Division, the Developmental Disabilities Council, and the Association for Retarded Citizens have met with parents in an effort to form a parent advisory committee to the Johnstone project.

❑The Division has made commitments assuring that Johnstone staff will not lose their jobs because of the closing.

❑In order to close Johnstone, the population of all ten developmental centers must be reduced by 229 persons, in addition to the population reductions necessary to meet the Vineland and Woodbine phase down targets.

❑The $7.0 million in state funds which will be available to operate Johnstone during SFY 1993 will remain in the Division's budget base in succeeding years to fund the annualized cost of 180 community placements for current residents of Johnstone and the other developmental centers.

❑The remaining 49 institutional vacancies will be created without displacing anyone on a community waiting list.

15X

- Of the 180 persons being placed directly in community homes, 84 will come from Johnstone, 23 from North Jersey, 32 from North Princeton and 41 from New Lisbon.

INTRODUCTION: A NEW VISION

On May 1, 1991, the Division of Developmental Disabilities submitted its plan to close the Johnstone Training and Research Center during fiscal year 1992, to the Senate and Assembly Appropriations Committees. The closure had been announced in the Governors budget message in February.

The original plan assumed that $5.2 million would be available to fund the cost of community placements necessary to effect the closure.

When the 1992 Appropriation Act was passed it permitted a longer period, two fiscal years, to close Johnstone and increased the level of funding available to complete the project. These changes in the fundamental assumptions underlying the plan necessitated this plan ammendment.

Within the Division of Developmental Disabilities, the closing of Johnstone was recognized as a first, possibly painful step toward the realization of a new vision of what the service system for people with developmental disabilities should be. In the intense public debate that followed the announcement, it was driven home to us that we need to do a better job of communicating that vision.

The Division's current system relies heavily on institutional care. In fact, experts speculate that New Jersey may currently have the largest institutional population of any state, relative to the state's general population. Other states have proceeded much farther in serving people with developmental disabilities in the community. One state has eliminated institutional care entirely. Others are close to doing so.

We envision a system of supports and services that allows most of the people currently living in developmental centers to live and work in the community in a wide variety of living situations appropriate to their needs and circumstances. This community-based system would be backed by a network of smaller developmental centers, all meeting Federal Intermediate Care Facility for the Mentally Retarded (ICF/MR) standards.

16X

We envision that the number of people in developmental centers will eventually be small--we do not know how small. The world is changing. It has been shown dramatically that many of the people who formerly lived out their lives in developmental centers have the capacity to live full lives in the community, work at meaningful jobs and enjoy full citizenship. It would be tragic if those of us who care most about people with developmental disabilities limited their potential for growth and development through underestimating their capacities.

In addressing the needs of most people with developmental disabilities for greater freedom and participation in community life, the Division will not forget those for whom community supports have not yet been developed or who cannot currently benefit from community placement, because of the severity of their disabilities, or their medical fragility--or for any other reason. For the foreseeable future, the small developmental center, providing high standards of care, will have a role in the system.

We are a long way from realizing this vision. Doing so will mean continuing the commitment of the past thirteen years to reduce the size of the developmental center population. The closing of Johnstone is an important step in this direction.

BACKGROUND: CONTINUING COMMITMENTS

Every year for the past thirteen years, the Division of Developmental Disabilities (DDD) has moved about 300 people with mental retardation from its institutions into the community. In 1978, the total institutional population was 7932. In 1991, it is 4992. For thirteen years, the Division has managed to develop appropriate community placements and services for all of these individuals. None of them are homeless. None go without needed support services. None have been deserted by the Division. They all live in real homes.

Today the Division serves over 18,000 people; more live in the community than live in institutions. (See Appendix A.) Many people who once lived at Johnstone and at other developmental centers now live productive lives in their own homes. Both the Division and community advocates are proud of this. At the same time we understand the fears of the critics of the Johnstone closing--this kind of change can be painful. We agree that what happens to the people at Johnstone, residents and staff, is important.

17X

We have taken a careful, gradual approach which some have criticized as too slow. But we have always recognized that our population has needs that don't go away. We know that we cannot place institutional residents in the community without first creating appropriate placement resources and support systems including employment, medical assistance, etc., and we have done so. The Division is committed to the principle that no institutional resident will be moved into the community without an appropriate placement and appropriate support services. This commitment stands on thirteen years of performance. This commitment will be completely upheld in the coming months at Johnstone.

The Division is further committed to a guarantee that Johnstone residents will sustain or improve their current quality of life after the closing. To give real meaning to this commitment, the Division has cooperated with the Developmental Disabilities Council to secure the services of Conroy & Feinstein, a research firm with a national reputation, to evaluate the impact of the closing on each and every Johnstone resident. If this study finds that any former Johnstone resident has a worsened quality of life in his or her new placement, the Division will take immediate corrective action.

Six hundred and twenty three (623) developmental center beds will be phased out during 1991 and 1992, an average of 311 per year. This is, as you can see, very much business as usual. There is no reason to suggest that the resulting community placements constitute any departure from the Division's long-term commitment to serve persons with disabilities in the community whenever possible.

Both the plan to close Johnstone and the increasing commitment to community living have been on the agenda for some time. In 1989, the Legislature mandated that this shift in priorities be reflected in the Human Services Bond issue. Of the $35.8 million for the Division of Developmental Disabilities, $25.8 million was targeted to the development of community services. This sent a clear signal that the Division should direct its resources into the community.

The Division's long-term commitment to reducing the population of developmental centers has long been understood and accepted by advocates for people with disabilities, the Office of Management and Budget, the Division of Building and Construction, the Office of Legislative Services and other governmental agencies involved with the Division's resource decisions. Consequently, decision-makers have limited

investments in the institutional system whenever it was possible without jeopardizing the residents' well-being.

At several points during the 1980's, there have been calls for the closure of Johnstone. In 1987, the Division indicated its intention to close Rice and Gregory Halls, the units containing the majority of the beds at Johnstone. A five-year plan developed in 1988 targeted the entire facility for closure but funds were not committed to the project at that time.

WHY THE MOVE TOWARD COMMUNITY?

The Division's shift toward serving people with developmental disabilities in the community is part of a national trend in this direction. In 1977, the total expenditures of community services programs in the nation was $879 million. By 1988, total expenditures had reached $5.6 billion. What these numbers reflect is a massive redirection of service priorities from traditional institutions into the community.

This trend toward community services has little to do with the current hard economic times, though, in this case, economics have tended to accelerate the process. The rationale behind it is clear and simple: people with developmental disabilities belong in the community. Excluding them from living, working and playing in community settings is wrong.

It is possible to provide all the protection, service and long-term security that people with developmental disabilities need in independent living situations, supervised apartments, group homes and skill development homes. People with developmental disabilities can and should live, work and receive services while living in real homes. It's as simple as that.

Experience has shown that former institutional residents who are placed in community settings become more independent and rapidly gain skills associated with living a more normal life. Participating in ordinary activities--taking care of a home, going to work or day program, going to the movies with friends--are not a normal part of an institutional program--at best, they can only be simulated.

19X

As Senator Chafee, a respected advocate for improved services, said in a recent article, "None of us would choose to live in a traditional institution if there were an alternative." To that end the Division is committed to improving the range of options designed to support individuals in the community. We agree with the Senator that creating the alternatives is the major task facing state agencies serving people with developmental disabilities.

New Jersey is not in the lead in the movement to serve people with developmental disabilities in the community. In fact, only three other states have more people in institutions at this point--and all of them, Texas, New York and California, have much larger populations. Other states have proceeded much further in the development of community-based service systems and reducing the number of people living in institutions.

We certainly understand that closing an institution causes very strong emotions in some parents and institutional staff members. We don't want to ignore these feelings, but we also want to say very clearly that the future for people with developmental disabilities is in the community. Will New Jersey be ready for that future?

WHY CLOSE JOHNSTONE?

A great deal of misinformation has been given out about the abilities of Johnstone's residents, the nature of Johnstone's resources and the quality of its physical condition. We want to set the record straight. Many Johnstone residents are very good candidates for immediate community placement; others can benefit from the improved programming and physical environment provided in ICF/MR settings. These residents function, by and large, at much higher intellectual levels than most other developmental center residents. Many visit community settings for extended periods of time; some work in the community and return to the institution in the evening. Contrary to statements of opponents of the closing, very few are blind, have multiple disabilities or are medically vulnerable.

Only 40 of the residents at Johnstone live in units certified under Intermediate Care Facility for the Mentally Retarded (ICF/MR) standards. (see Appendix C for an explanation of ICF/MR program.) These standards require higher staffing levels. As a result, Johnstone has the poorest staffing ratio in the developmental center system.

20X

Johnstone is also in very poor physical condition. Of the 229 people who live at Johnstone, only 91 live in reasonably acceptable conditions in the Hayes and Valentine units. The majority of Johnstone's residents live in Rice and Gregory Halls, each with 69 residents. These dilapidated three-story buildings were considered incapable of being renovated to ICF/MR standards as early as 1977. They have leaky roofs, fallen plaster, heating systems that cannot be controlled, wet basements and inadequate storage space. These living units are hopelessly antiquated.

There are a host of other capital problems at Johnstone. Steam lines, boiler replacements and road upgrades are also needed. A 1990 catalogue of the critical needs exceeded $12 million. A more recent estimate rose to $15 million--and this would merely make the facility habitable; it would not make it possible to certify additional beds under ICF/MR.

Prior to the decision to close Johnstone, the Division had decided that Johnstone could not be kept open without addressing these critical needs. Given the commitment to move toward community based services, this kind of investment would have been clearly inappropriate. There was no reason to believe that either the legislature or the Department of Treasury was prepared to make a large investment in institutional services--given a long-standing commitment to institutional reductions. It is difficult to see how any other choice could have been made. The current economic crisis merely hastened the inevitable.

In the past, the Division has achieved community placements for developmental center residents who need them through a strategy of closing units of facilities not certified under ICF/MR. This strategy has obvious merit since certified units have better environments and greater professional staff resources than non-ICF/MR units. They also have direct care staff ratios that approach those found in community homes.

This strategy has allowed improvement in the lives of all those still living in developmental centers, not just those who move to community homes. As overall populations decline and relative staff ratios increase, the quality of life for all is improved.

21X

Uncertified beds have declined from 2322 in 1978, to 1198 today. (See Appendix D.) Current plans call for the Division to place 256 people into community homes from the phase-out of non-certified beds at Vineland. One hundred Woodbine residents will be placed into community homes from non-certified beds by 1993. The closure of Johnstone, a largely non-ICF/MR institution, was the next logical step toward elimination of all non-ICF MR beds.

THE RESIDENTS OF JOHNSTONE

Our primary concern is the care and quality of life of the 229 residents now living at Johnstone. We recognize that Johnstone has been their home, and that moving from that home will be somewhat frightening. As we are when we face similar changes, they may be apprehensive about leaving a familiar place, about meeting new people and about being in new situations.

The Division is working with each resident to be sure that the placement decision made reflects the resident's needs and individual preferences. The Developmental Disabilities Council, in cooperation with the Division and the Association for Retarded Citizens/NJ, has initiated a project that seeks to address the unique needs of the residents of Johnstone during the closure. One aspect of the project will link Johnstone residents with self-advocacy groups. This will help to provide them with the support needed during this period of transition, be it to the community or to another developmental center.

PLACEMENT PLANS

Personal interviews and case record reviews have confirmed that the people who live at Johnstone can be far better served in other settings. All persons receiving services from the Division of Developmental Disabilities must have an individual habilitation plan (IHP) which outlines their service needs, their preferences and the steps necessary to achieve their developmental goals. (For a fuller description of the IHP see Appendix E.)

Placement plans have been developed for Johnstone residents that will meet the needs and preferences outlined in their individual habilitation plans. Where community placement has been identified as the appropriate service, community liaison staff are working with developmental center staff to develop transitional plans. This is particularly important because institutional staff are not always aware of the service options available in community settings. If families have expressed a preference for specific placement locations, these are being considered. (see Appendix F for placement plans.)

The people who will be transferred into other developmental centers will be moved into living units which are ICF/MR certified. Most will go to New Lisbon, North Princeton and North Jersey Developmental Centers. Persons long slated for community placement will be leaving these centers to free space for Johnstone residents. Those people moved to North Princeton Developmental Center will be living in 8-person group homes on the grounds of that facility which were constructed as transitional residences for North Princeton Developmental Center residents awaiting community placement.

Community service liaison staff are working with the developmental center staff at New Lisbon Developmental Center, North Princeton Developmental Center, North Jersey Developmental Center, Vineland Developmental Center, Hunterdon Developmental Center, Woodbridge Developmental Center and Green Brook Developmental Center to review the case records of those persons who have community placement as one of the goals of their Individual Habilitation Plans. Many of these people have waited for community placement for a long time. The Johnstone closure will give some of these individuals the opportunity.

Recommendations for specific types of community homes have been made for some Johnstone residents and the matching process has begun. Transition plans are being developed for each of these individuals. These plans will be modified before being finalized as individual likes and dislikes are accommodated. In no case will any resident of Johnstone or any other developmental center be moved until an appropriate alternate program is in place.

It would be desirable for all of Johnstone's residents to move directly to community homes. The achievements of other states have made this clear. But our support system, while good and getting better, cannot yet reach that goal. Nor do we have sufficient funds to achieve it. Services to the people who now live in Johnstone will be significantly better. They will be moved one step closer to reaching the independence that is their right. And, the entire institutional system will be significantly reduced in the process. The outcome, while not the best, is the best possible given current realities.

THE JOHNSTONE FAMILIES

Some of the families of Johnstone residents are extremely upset about the closing of Johnstone. We at the Division certainly understand these feelings and feel compassion for the pain that the plan to close Johnstone has caused.

All parents worry about their children's future. Parents of children with developmental disabilities are no exception--in fact, they have exceptional cause to worry because of the vulnerability of their children. An institutional placement seems like a permanent solution to the problem--the institution will always provide food, shelter and basic care. We do not blame people for embracing this solution--in the past, developmental disability professionals may well have told them that it was the only thing for them to do. The Division's announcement of the Johnstone closing revives all of the fears and anxieties that parents have about what will happen to their children in the coming years.

Institutional closings almost always engender these responses in the beginning. Follow-up studies from other institutional closings indicate that those families with a son or daughter placed in the community are overwhelmingly more satisfied with the community placement after a short time.

For those parents with a family member moving to another institution, the move will generally be from a decaying, marginal environment with the lowest number of staff per resident in the whole system to living units that meet the extensive health, safety and staffing requirements of regulations for Intermediate Care Facilities for the Mentally Retarded (ICF/MR).

24X

The Division fully endorses the program to support the families currently being developed by the Developmental Disabilities Council in conjunction with the Association for Retarded Citizens. This plan will include a toll-free hotline to answer questions and address concerns, parent support groups, assistance in learning how to participate effectively in Division planning for the resident and opportunities to network with parents of Division clients who live in a variety of living arrangements. The plan will afford parents--and residents--opportunities to learn about the full range of available options.

Additionally, the Division, the Developmental Disabilities Council, and the Association for Retarded Citizens have formed a parent advisory committee to the Johnstone project. Parent representatives from each of the developmental centers primarily affected will be members of the committee and will have the opportunity to provide input during each stage of the implementation of the project.

THE JOHNSTONE STAFF

Our primary focus is on the best interests of Division clients--and we strongly believe that the continued development of community services is very much in their interests. It is not, however, our intention to forget about the interests of those who have chosen careers in service to the Division and its clients.

Both Commissioner Alan J. Gibbs and Dr. Nicholas have made the commitment that Johnstone staff will not lose their jobs as a result of the closing. Commissioner Gibbs has directed that, vacancies at other Human Services facilities may not be filled until the transfer of Johnstone employees has been considered.

There are three large institutions within reasonable commuting distance of Johnstone--New Lisbon Developmental Center, North Princeton Developmental Center and Trenton Psychiatric Hospital.

There are also employment opportunities available in the community service network. A survey of Johnstone employees was conducted to elicit their preferences for work locations after the closure.

25X

Tours of the possible work locations have been arranged and interviews are being set up as employees respond and vacancies are posted. Special shared job arrangements will be permitted as the phase-out proceeds in order to accommodate the operational needs of both the receiving facility and Johnstone.

Nevertheless, there will be some staff who remain at Johnstone through the closure period for whom immediate vacancies at other facilities will not be available. These employees will be transferred to other work locations with their Johnstone positions. Those positions will be red-lined. When a position at the receiving facility becomes vacant, the Johnstone employee will be transferred into it and the then vacant Johnstone position terminated. We believe that Johnstone staff can be accommodated in the Human Services system.

FUNDING

In order to close Johnstone, the population of all ten developmental centers must be reduced by 229 persons, in addition to the population reductions necessary to meet the Vineland and Woodbine phase down targets. The $7.0 million in state funds which will be available to operate Johnstone during SFY 1993, will remain in the Division's budget base in succeeding years to fund the annualized cost of 180 community placements for current residents of Johnstone and the other developmental centers. (The original plan envisioned only 125 placements directly into the community.)

The remaining 49 institutional vacancies will be created in the following manner. Ten people now living in developmental centers are in category #1 of the community waiting list and are being placed as the result of other funded initiatives. Twenty-three people are being placed in skilled nursing facilities as a result of their need for skilled nursing care. The remaining reduction will be achieved as follows. Annually about 100 vacancies occur in the developmental centers as the result of out-of-state moves and deaths. They are usually dedicated to emergency placements. Sixteen of these vacancies will be dedicated to the Johnstone phase down. We know that some are concerned about possible impacts of the closing on community waiting lists. The closing will not displace a single person currently waiting for residential service in the community. In fact, the Division is committed to seeking funding each year to meet the community residential needs of residents of developmental centers and persons on the community services waiting list.

Of the 180 persons being placed directly in community homes, 84 will come from Johnstone, 23 from North Jersey, 32 from North Princeton and 41 from New Lisbon. (The charts in Appendix F show placement plans.)

All placement plans are the result of IHP reviews, supplemented by transitional IHP meetings. They may change slightly as individual likes and dislikes are accommodated.

A further issue to be addressed is the maintenance of ICF/MR revenues. Although only 40 beds at Johnstone Training & Research Center are certified, they generate approximately $1.3 million per year in revenue. If funding for the Johnstone closure is to be available for community programs and if it is to generate the projected savings, that revenue cannot be lost to the system as a whole.

To that end, the Division plans to certify replacement beds in two cottages at the North Jersey Developmental Center. North Jersey has a sufficient number of direct care positions, but its professional and support positions are not adequate to achieve certification in the two cottages. Thirty-five positions are necessary; the North Jersey Developmental Center check cut cap for full time positions must be adjusted from 946 to 981. The annualized cost of certification will be approximately $800,000 but about $2.8 million in federal revenue will be generated for a net annualized increase of approximately $700,000.

FACILITY

Neither the Division of Developmental Disabilities nor the Department of Human Services has any plans for the further use of the Johnstone facility. As a result, the Department has declared the facility as surplus. This means it will be offered to other State departments. If no State departments need the facility, it will be sold.

CONCLUSION

Johnstone will be closed. Its closure is part of a long-term commitment to the building of a community-based system of services for people with developmental disabilities.

APPENDIX A

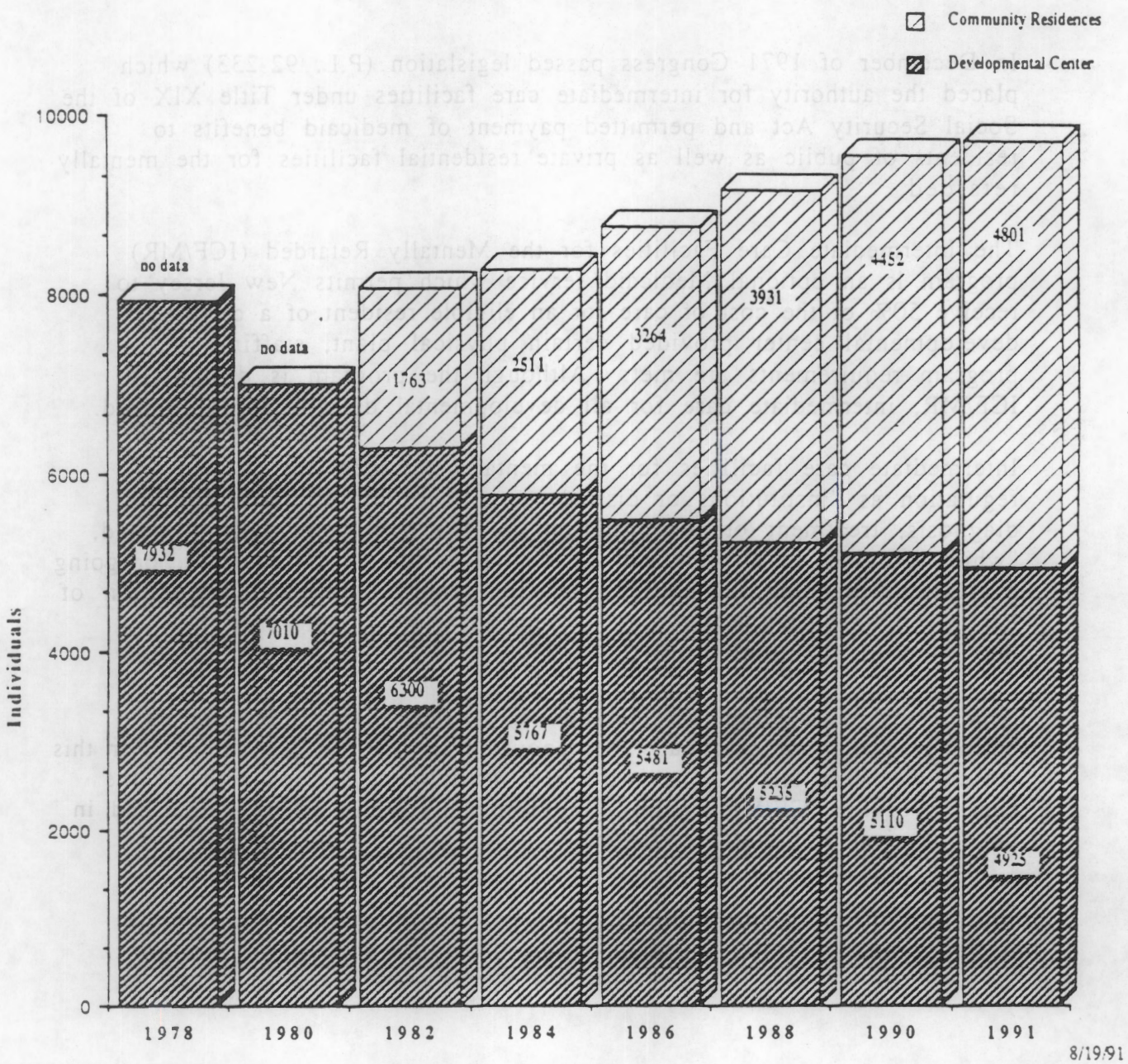
Services Provided by the Division of Developmental Disabilities

The Division of Developmental Disabilities (DDD) is the state agency with primary responsibility for providing services to people with developmental disabilities. A component of the Department of Human Services, the Division serves people with Autism, Mental Retardation, Cerebral Palsy, Epilepsy, Spina Bifida and Head Injuries. It provides guardianship services, various types of day programs and in-home supports for several thousand people.

The Division supports a network of community residential programs which serve approximately 3500 people statewide. Staffed living arrangements include group homes and supervised apartments. Skill development homes provide enriched foster placement for people whose training needs vary in intensity. Supported living programs serve people who are able to live in their own apartments but who require support and assistance on a limited basis. A full range of day programs is provided with increasing emphasis on supported employment. The Division also operates ten developmental centers housing 5000 people. In total, the Division of Developmental Disabilities serves 18,000 developmentally disabled people and their families.

DIVISION OF DEVELOPMENTAL DISABILITIES
RESIDENTIAL PROGRAM CENSUS

(All figures based on June 30)



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APPENDIX C

Intermediate Care Facilities for the Mentally Retarded (ICF/MR program)

In December of 1971 Congress passed legislation (P.L. 92-233) which placed the authority for intermediate care facilities under Title XIX of the Social Security Act and permitted payment of medicaid benefits to residents of public as well as private residential facilities for the mentally retarded.

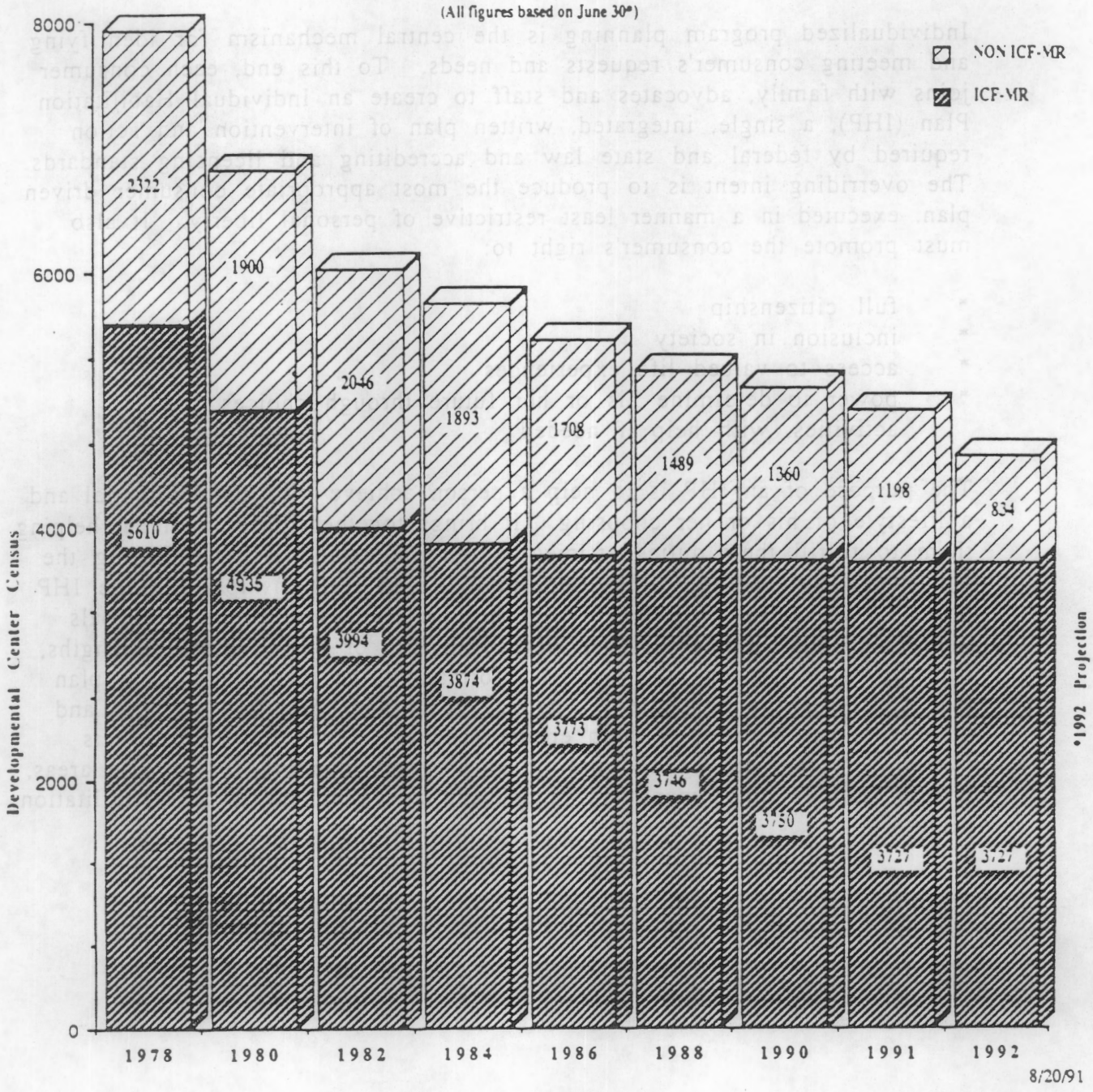
The Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program is an optional Medicaid service which permits New Jersey to receive 50% of the cost of care for an eligible resident of a certified developmental center provided certain physical plant, staffing and program requirements are met. Although the program is designated ICF/MR, intermediate care for all developmental disabilities is covered.

Intermediate care facilities for the mentally retarded are defined in regulation as "institutions or distinct parts there of, primarily for the diagnosis, treatment or rehabilitation" of the developmentally disabled, "which provide, in a protected, residential setting, individualized, on-going evaluation, planning, 24-hour supervision, coordination and integration of health or rehabilitative services to help each individual reach his maximum of functioning capabilities."

New Jersey has a large, old institutional physical plant. Many of its buildings could not practically be renovated to ICF/MR standards. For this reason we were left with a two-tiered institutional system with all the benefits of the ICF/MR program in some units while others languished in poor physical and staff condition.

30X

DIVISION OF DEVELOPMENTAL DISABILITIES
DEVELOPMENTAL CENTER ICF MR/NON-ICF MR



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APPENDIX E

Individual Habilitation Plans

Individualized program planning is the central mechanism for identifying and meeting consumer's requests and needs. To this end, each consumer joins with family, advocates and staff to create an Individual Habilitation Plan (IHP), a single, integrated, written plan of intervention and action required by federal and state law and accrediting and licensing standards. The overriding intent is to produce the most appropriate consumer driven plan, executed in a manner least restrictive of personal liberty. It also must promote the consumer's right to:

* full citizenship
* inclusion in society
* access to valued life experiences
* power to determine his or her future through choices and activities, with help if needed

The purpose of an IHP is to help a person achieve maximum potential and a lifestyle of his or her choosing. It brings together those involved, helping them to fulfill their duties efficiently and understand issues affecting the consumer's well being, career opportunities and relationships. In the IHP process, the consumer shares his or her preferences and personal goals with other team members, who work with him or her to assess strengths, capabilities and needs. Using this information, the team develops a plan that addresses the consumer's personal goals and identifies services and other supports required to help ensure success. Since the IHP reflects overall service planning and individual program planning for all life areas, it may include other mandated plans such as an education or rehabilitation plan.

32X

DIVISION OF DEVELOPMENTAL DISABILITIES - JOHNSTONE INITIATIVE

Projected Developmental Center Placements from Johnstone Training & Research Center

	DEVELOPMENTAL CENTER PLACEMENTS									
	NPDC	NJDC	NLDC	WBR	HDC	WBI	VDC	DCA	Assignment Pending	TOTAL
JTRC	32	28	36	1	7	4	3	1	32	144

DEVELOPMENTAL CENTERS

NPDC-North Princeton	NLDC-New Lisbon	HDC -Hunterdon	VDC -Vineland
NJDC -North Jersey	WBR -Woodbridge	WBI -Woodbine	DCA -Ancora

33X

APPENDIX F

10/15/91

DIVISION OF DEVELOPMENTAL DISABILITIES - JOHNSTONE INITIATIVE

Projected Community Placements from Developmental Centers

COMMUNITY PLACEMENTS

	GH	SNGH	SA	SD	TOTAL
JTRC	34	21	19	10	84
NJDC	3	0	0	20	23
NPDC	1	12	0	19	32
NLDC	4	0	1	36	41
TOTAL	**42**	**33**	**20**	**85**	**180**

DEVELOPMENTAL CENTERS

JTRC -Johnstone Training & Research Center
NJDC -North Jersey
NPDC-North Princeton
NLDC-New Lisbon

COMMUNITY PLACEMENTS

GH -Group Home
SGH -Special Needs Group Home
SA -Supervised Apartment
SD -Skill Development Home

10/3/91

34x

APPENDIX F

AAMH

ASSEMBLY APPROPRIATIONS COMMITTEE

DECEMBER 11, 1991

Submitted by:
Marshall Bord
Nicole Alexick

Association for Advancement of the Mentally Handicapped
60 Prince Street
Elizabeth, NJ 07208-3261
Tel: 908 354-3040
Fax: 908 354-2665

35X

I am the legal guardian of my brother, Maurice Kaplan, who was born with Down Syndrome 53 years ago.

When he was 17, my parents placed Maurice in a private school in Vineland, NJ, known as The American Institute for Mental Studies. During most of his 36 years of residence there, the family felt that he was in a safe and progressive environment and he was happy.

When the school was sold to an Institutional Chain, Maurice became increasingly depressed and unhappy. The institution insisted in treating him for depression, refusing to acknowledge the possibility that they were contributing to his mental state. I strongly felt that his well-being was in jeopardy and made inquiries concerning potential alternatives.

I contacted a local organization known as the Association for Advancement of the Mentally Handicapped (AAMH) which was willing to work with Maurice. After a trial visit, the AAMH, Maurice and I jointly decided to pursue a permanent arrangement with this community-based organization. Details had to be worked out with the Division of Developmental Disabilities. This took several months. During this interval Maurice constantly inquired about my progress since he was very anxious to make the change.

On September 15, 1991, Maurice moved from the Vineland facility to a new 2-bedroom condominium apartment that he shares with another seriously handicapped person. For weeks after the transition, he could frequently be heard singing "Born Free".

Naturally, there are accommodation problems, but they are being handled with professional guidance from on-site supervisors.

During the several months that have elapsed, Maurice has become more of "his own person". He makes decisions about his own life. He is training for competitive employment and makes choices for his meals. In other words, he is living a more normal life than ever before.

The level of achievement that he is able to attain is problematical, however all indications seem to presage a very comfortable and meaningful life style for him. The move to a community setting has been salutary in every respect. All personal visits and telephone communications with Maurice reflect enthusiasm for and happiness with his new environment.

arc

A voluntary, non-profit association helping people with mental retardation in every county of New Jersey

Frank Nardi
President

Paul A. Potito
Executive Director

Position Statement

The Executive Committee of the Association for Retarded Citizens of New Jersey reaffirms the position of our Board of Directors supporting the closure of the Johnstone Research and Training Center in Bordentown, New Jersey. The position to support the closure of Johnstone was made on February 28, 1991 at our bi-monthly board meeting by a vote of 22 to 1.

ARC/NJ's Board of Directors is composed of representatives from each of our local chapters as well as representatives of each of the state's 10 Developmental Centers' parents associations. The February 28, 1991 decision to support the closure was adopted as part of this Association's position on the Fiscal Year 1992 State Budget.

On March 26, 1991 the Executive Committee reaffirmed the position of the ARC/NJ Board of Directors to support the closure. The Executive Committee, however, adopted the following statement to clarify any misgivings by members of this association regarding the closure:

> ***ARC/NJ supports the closure of the Johnstone Research and Training Center as a necessary step - just one of many - and that manner of transition must be managed to deal with the distress and maximize the quality of life opportunities for the individuals served and their families.***

The position also included a paragraph that the move must facilitate a better way of life for the individual, and that the ARC would oppose any move that was without proper individual planning or was to a less desirable site.

<u>As of this date, 40 individuals residing at Johnstone have been moved to their new placements without parental or guardian appeal.</u>

Association for
Retarded Citizens
NEW JERSEY

985 Livingston Avenue ■ North Brunswick, New Jersey 08902 ■ 908/246-2525 ■ FAX 908/214-1834

With respect to these new placements, the ARC has monitored the closure by:

*meeting monthly with representatives from the Parents Associations of the North Jersey Developmental Center and the North Princeton Developmental Center with respect to the transition. Representatives from the Friends of Johnstone Develop mental Center were invited to these monthly meetings, and while they have not partici pated as of yet, we are pleased to learn that they will be attending soon.

*welcoming the input from representatives from eight of N.J.'s Developmental Centers at our Board of Director's meetings as well as our Residential Services Committee.

*meeting monthly with representatives from the Division of Developmental Disabilities, the Developmental Disability Council, the Rutger's Project, and Conroy & Feinstein Associates to discuss the monitoring of the closure.

*reviewing and commenting on the formal "Plan for Closure" of the facility issued by the Division of Developmental Disabilities on November 15, 1991.

The decision of the ARC/NJ's Board of Directors to support the closing of this institution was based on the following facts:

*180 of the 220 beds at the facility are not certified by the federal government and are considered substandard. This means poor staffing ratios, less upkeep of the buildings/facilities, no active treatment for residents, etc.

*The State of New Jersey has the highest number of uncertified beds in the country: 1,100. These beds are totally funded by state appropriations and do not qualify for one dollar of reimbursement from the federal government because they are considered substandard.

*Most parents/families do not view institutional placement as a residential place- ment option. This is illustrated by the fact that the waiting list for group home and other community residential options in N.J. is 3,400+ individuals and the waiting list for institutional placement is 103.

*Although less than 10% of New Jersey's citizens served by the Division of Develop mental Disabilities reside in state funded institutions, over 60% of the dollars for hous ing people with disabilities is spent on institutional care.

*Over the last ten years New Jersey's institutional population has decreased by 25% but the funding for institutions has increased by 350% in the same period.

The Association for Retarded Citizens of New Jersey hopes that it is the intent of this committee to ensure that the quality of life of individuals with mental retardation and other developmental disabilities is preserved. And, we hope that the impetus for this meeting was generated by concern for the welfare of the residents of the Johnstone Research and Training Developmental Center and not the displacement of unionized staff working at this facility.

Our position regarding the closure is motivated by a vision of a future without institutions as they exist today. Our position is based on a vision that all people regardless of their abilities or disabilities are given an equal chance to live a life based on:

*integration rather than segregation.

*freedom to make informed choices.

*independence rather than dependence.

We ask you to share with us in our vision. We ask you to view the closure of this institution as just one step of many toward bringing this population out of the dark and into the light.

Issued by: Frank Nardi, on behalf of the Executive Committee of the Association for Retarded Citizens of New Jersey

Regarding: The December 11, 1991 Public Hearing on the Closure of the Johnstone Research and Training Center

Date: December 10, 1991

Testimony of
Sandra Lee Porrata
12/11/91

When I was 19, my mother told me she was taking me somewhere special. I knew it was far away because she packed all of my clothes. We came to a place that looked like a hospital. My mother said I was going to stay there to learn how to take care of myself. Later, someone told me I was at the Vineland State School.

It was awful. All I could do was cry and call for my mother and my grandmother. I was scared because I didn't know anybody; I was all by myself. Anything I needed I had to get on my own. I lived at Vineland for 16 years.

One day I made up my mind that I was going to get out. I spoke to my case worker and asked if I could get out. He said he would work on it.

He came back and said he had to write a letter to my mom. My mom didn't want me home; she wanted to keep me away from my family. But I still wanted out.

One day, my caseworker called me into the office. He said he found a lady who needed someone to live with her. A few weeks went by and then she came. Her name was Mary.

I liked her very much. Mary said she needed somebody to live with her and she picked me. I told her I would like to live with her until I got used to being on the outside.

I liked it with Mary. I had my own room, my own TV, my own telephone -- everything I wanted and never had before. I was independent; I could come and go as I pleased. Anything was better than Vineland.

I started going to United Cerebral Palsy's adult program and learned cooking and other things. I lived with Mary for four years, and then it was time to leave and do more with my life.

In 1986, I met my husband, Junior, at camp. We got married and moved to the South Bronx for awhile, but it was a bad place to live -- we got robbed every month. Now we live in Long Branch, New Jersey.

It was hard to leave Vineland because I had friends there. When I left, I cried because I knew people there who weren't going to get out. It was very hard, very emotional. I cried.

I was scared to get out; very scared to be around people like you. I didn't talk. I didn't go places. I was afraid of people looking at me and wondering what I was doing there.

But now, I don't care what people think. I'm normal. I've got a mind. I know what to say around people.

You have to make up your mind. You have to want to get out. And if you do, make your move. You've got to live now, or you are going to be developmentally disabled and die in an institution.

UMD
NEW JERSEY
University of Medicine & Dentistry of New Jersey
Robert Wood Johnson Medical School
Developmental Disabilities

Testimony

to the

Assembly Appropriations Committee

regarding

Johnstone Training Center

December 11, 1991

Submitted by:
Deborah M. Spitalnik, Ph.D.
Executive Director
The University Affiliated Program of New Jersey
Associate Professor of Clinical Pediatrics
University of Medicine & Dentistry of New Jersey
Robert Wood Johnson Medical School

42X

Chairman Watson and other member of the Assembly Appropriations Committee, I appreciate the opportunity to testify before you today. My name is Deborah Spitalnik, Ph.D., and I am Executive Director of the University Affiliated Program of New Jersey, part of the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, where I am also an Associate Professor of Clinical Pediatrics. The University Affiliated Program of New Jersey is one of a network of 45 federally designated programs nationwide providing state of the art training, technical assistance, service, research, and information dissemination in developmental disabilities. In my role as Director of New Jersey's University Affiliated Program and serving as President of the American Association of University Affiliated Programs I am acutely aware of the growing national vision of full participation in community life for people with developmental disabilities and the affirmative steps we must take in New Jersey, as we are lagging behind where we must be.

The passage of the Americans with Disabilities Act in 1990 with its sweeping civil rights protections mandates the need for accommodation in all aspects of society to enable persons with disabilities, including people with developmental disabilities to be full participants in community life. This landmark legislation came into being in recognition of the discrimination which accrues to people with disabilities and the consensus among

the American people that it was time to end this discrimination and build a more inclusive society.

The federal Administration on Developmental Disabilities has adopted a national agenda which is centered on community inclusion. This emphasis on community inclusion extends to school, play work and living.

The American Association on Mental Retardation, the oldest established professional organization in Mental Retardation recognizes the importance of community life in its newly revised definition of mental retardation. This definition establishes community as the context for the measurement of mental retardation and assumes the necessity of community life for the growth and enhancement of the skills of persons with mental retardation.

Through the growing body of experience nationwide, life in the community- with appropriate and adequate supports, enables persons with developmental disabilities to express their capacities, capabilities and gifts. Over 32,000 individuals with mental retardation/developmental disabilities are working in supported employment across the country(Shafer, Revell & Isbister, in The Journal of Vocational Rehabilitation, Vol 1. No. 1, 1/91). Over 100,000 persons with mental retardation live in small community residences across the country (Anderson, Lakin, Bruininks & Hill, 1987).

Increasingly persons with developmental disabilities are telling us, directly and sometimes indirectly that they aspire to the same things in their lives that we all aspire towards. A place to live that is truly one's own, a job, more independence, choice

and more relationship- interdependence with friends and family. Being part of a community and the chance to be heard and valued.

We have the ability to affect these outcomes for people with developmental disabilities, but **in New Jersey we are lagging behind**. Despite the self-image we hold as a state as progressive, forward thinking, and maintaining life quality for our state's citizens, in the forward movement of services for persons with mental retardation and developmental disabilities we are lagging behind the nation.

Concomitant with the development of smaller community based services and supports nationally has been the reduction in larger congregate residential facilities. The State of the States in Developmental Disabilities (Braddock, Hemp, Fujiura, Bachelder & Mitchell, 1990) published by the UAP in Illinois, which is the Third National Study of Public Spending for Mental Retardation, and the Fourth study now in process, document the ways in which New Jersey has fallen behind these positive national trends.

New Jersey ranks as the fourth highest state in the country in terms of the numbers of persons institutionalized (University of Illinois at Chicago UAP, 1991). Expressed differently, 46 states have fewer numbers of persons institutionalized. It should also be noted that of New Jersey's (almost 5000) institutional beds, **1500 of these beds fail to achieve even the most basic federal standards.**

New Jersey ranks 34th in the percentage of reduction of our institutional beds, for the period of the mid to late 80s(Braddock etal 1990).

New Jersey is 27th in spending in mental retardation and developmental disabilities. What we do spend we persist in a disproportionately higher rate of spending for institutions rather than community ((University of Illinois at Chicago UAP, 1991).

Significant institutional closings have occurred or are planned in other states. New Hampshire and the District of Columbia no longer have any institutions; they are totally community based systems.

It is time for us in New Jersey to catch up. The closing of Johnstone represents an important step toward achieving our rightful place as a state that demonstrates its commitment to community services and lives of quality for New Jerseyans with developmental disabilities and their families.

We can do better than this in New Jersey.

ALAN J. GIBBS, COMMISSIONER
DEPARTMENT OF SOCIAL SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES
CN 700
TRENTON, NEW JERSEY 08625-0700

DECEMBER 9TH, 1991

DEAR COMMISSIONER GIBBS:

I AM WRITING ON BEHALF OF ALEX GOBRUK (A.K.A. ALEX GOBRUKOVICH) WHO IS A CLIENT OF D.D.D.

ALEX HAS BEEN A PATIENT AT THE BERGEN PINES PSYCHIATRIC HOSPITAL FOR THE PAST TWO YEARS. HE WAS PLACED THERE AFTER AN UNSUCCESSFUL STAY AT A GROUP HOME. I AM THE ONLY PERSON WHO VISITS ALEX AND BECAUSE I FELT HE WAS MISPLACED TRIED UNTIL NOW TO HAVE HIM PLACED IN A MORE APPROPRIATE SETTING. ALEX IS MENTALLY RETARDED AND THE WARD HE RESIDES ON IN BERGEN PINES IS FOR PSYCHIATRIC PATIENTS. DURING HIS TWO YEAR STAY ALEX HAS SUFFERED AND LOST GROUND BECAUSE HE WASN'T PROPERLY PLACED. THE STAFF AT BERGEN PINES HAS DONE AN EXCEPTIONAL JOB IN TRYING TO ADAPT TO HIS NEEDS BUT WERE UNABLE TO PROVIDE THE SERVICES HE REQUIRES.

I HAVE RECENTLY BEEN ADVISED BY YOUR STAFF THAT ALEX WILL BE PLACED IN THE NORTH

PRINCETON TRAINING FACILITY. THIS PLACEMENT I UNDERSTAND WAS COURT MANDATED DUE TO THE INTERVENTION OF THE PUBLIC ADVOCATE. I TAKE THIS NEWS WITH MIXED FEELINGS. I CERTAINLY AM HAPPY TO SEE ALEX BEING PLACED HOWEVER THE DISTANCE FROM MY HOME TO NORTH PRINCETON IS SUBSTANTIAL. SINCE I AM THE ONLY PERSON TO VISIT ALEX I WOULD LOVE TO SEE HIM PLACED IN A FACILITY IN NORTH JERSEY. THE REASON I AM ASKING FOR THIS IS THAT ALEX'S MOTHER RESIDES IN A NURSING HOME IN HACKENSACK. (5 MILES FROM THE TONNELE TRAINING CENTER). HIS MOM IS 78 YEARS OLD AND HAS NO WORLDLY POSSESSIONS BUT ALEX. HIS PLACEMENT IN PRINCETON WILL REQUIRE MY DRIVING OVER 250 MILES (PICKING UP AND RETURNING) FOR ALEX TO SEE HIS MOTHER.

I HAVE CONSULTED WITH A NUMBER OF PROFESSIONALS CLOSE TO ALEX AND HIS MOTHER AND THEY ALL FEEL THIS DISTANCE WILL CAUSE AN UNDUE HARDSHIP ON BOTH OF THEM. DUE TO THE DISTANCE INVOLVED I WILL NOT BE ABLE TO HAVE ALEX SEE HIS MOTHER A FEW TIMES EACH MONTH. WITH MY WORK SCHEDULE IT WILL BE EXTREMELY DIFFICULT FOR ME TO FACILITATE THESE MEETINGS. I AM THEREFORE

Requesting that Alex be placed in the North Jersey Training Center in Totowa or in a group home in close proximity to Hackensack.

Alex has already lost two years of potential growth due to his inappropriate placement. It has caused a great deal of weight loss to occur and it is my belief that he is depressed. Alex's behavior is much better when he does not feel the separation from his mother. The initial separation from his mother in 1982 left him a confused, disoriented person and led to his acting out and being placed in Bergen Anes from a group home setting. Please reconsider his current placement to a facility in the Hackensack area.

I am enclosing letters from four professionals who are close to the Cosbuk's case and who also feel that a placement in the Hackensack area would benefit Alex and his mother.

Thank you for your attention to this matter

Sincerely,

Gerard Russo, guardian

180 Sunset Ave North Arlington N.J. 07031

201-997-9571

49x

State of New Jersey
DEPARTMENT OF HUMAN SERVICES
CN 700
TRENTON, NEW JERSEY 08625-0700
(609) 292-3717

ALAN J. GIBBS
Commissioner

November 22, 1991

Gerard Ruane
100 Sunset Avenue
North Arlington, NJ 07031-5929

Dear Mr. Ruane:

Please be advised that your recent correspondence to Governor Florio has been referred to me.

I have asked Robert Nicholas, Director of our Division of Developmental Disabilities, to look into this matter and you will be hearing further from him in the near future. In the interim, if the need arises you may contact him at (609) 292-7260.

Sincerely,

Alan J. Gibbs
Commissioner

AJG:lal

c. Robert Nicholas

New Jersey Is An Equal Opportunity Employer

50X

NORTH JERSEY
WEDNESDAY, APRIL 17, 1991
THE RECORD



No place like home

The acute psychiatric ward at Bergen Pines County Hospital is not a place for anyone to call home. But Alex is forced to live there.

He's retarded. The state says there's no place else for him to go. He sleeps in a locked ward. Tonka toys and Matchbox cars sit on the window sill. Alex's crayon drawings line the walls.

Do you like living here, Alex?

"No. I want to go out. I want a group home," he says.

What did you draw?

"Animals. Trees."

Do you want to stay here?

"I want to go out of here."

Alex is 41 years old. He's 6 feet tall and has the mind of a child. He is like the lone piece of a puzzle that fits nowhere.

For most of his life, Alex lived with his mother in Bayonne. He took care of her when she got sick. Now his mother is in a nursing home. She always feared what would happen to her son when she could no longer care for him.

The mother turned to a family friend, Jerry Ruane, who promised to look after Alex. At first, Alex was placed in a group home in Bergen County. But he "acted out," as his social workers say, and hit someone and broke things. He was taken to Bergen Pines. "Dumped" would be a better word.

Alex was admitted to the acute psychiatric unit, where patients with episodes of mental illness — such as suicide attempts, depression, or schizophrenia — stay 30 to 60 days.

Alex has been there since December 1989.

The Bergen Pines staff knows Alex doesn't belong there, but their only option is to put him out on the street. So he stays in the hospital ward, where he can't walk down a street, pick a flower, or wave to a neighbor.

In addition, taxpayers have been paying $450 each day to keep Alex in this expensive psychiatric ward. He's not alone. Four similar patients admitted to the psychiatric unit wait for placement, officials say.

Meanwhile, some psychiatric patients have been turned away because the unit is filled.

Alex, like the others, is "dually diagnosed," which means he's developmentally disabled and mentally ill. But his social workers say that Alex has been treated with medication and is doing well.

"He has a low level of frustration, like a child. If he's supervised by trained professionals, he will be no problem at all," says Arthur R. Dinkel, a social worker who, like others at Bergen Pines, has grown attached to Alex.

The psychiatric staff believes that Alex, who loves to draw and play with toy trucks, belongs in a group home, and twice a Superior Court judge ordered the state Department of Developmental Disabilities to put him in one.

But Bergen Pines staff say they get nowhere with the department.

We're working on it. It's on a priority list. Any day now.

Ruane worries. Alex has gained more than 60 pounds. He rarely gets out — only when Ruane takes him out to a toy store, or to visit his mother.

"A staff member took him out for his birthday. They try," he says.

A state that can spend $450 a day to keep Alex in a place he doesn't want to be can't find the money for group homes.

Ed Rogan, a spokesman for Human Services, says the state is putting more money into community programs. Still, more than 4,000 wait. Rogan also says the "dually diagnosed" are especially difficult to place.

"People may be in a setting that's not perfect for longer than you might like," Rogan says, unofficially nominating himself for the understatement-of-the-year award.

Ruane, meanwhile, worries what he'll say when Alex's mother asks about her son, and how he's doing without her.

REGENT
CARE CENTER
50 Polifly Road
Hackensack, NJ 07601
201-646-1166
FAX: 201-487-3835

December 5, 1991

To Whom It May Concern:

I have known J. Gobrukovich since January, 1990. My first encounter with her was as the Charge Nurse on the unit where she lives. Ms. Gobrukovich spoke about her son, Alex, during my year of daily one-on-one conversations with her. She is a kind, compassionate woman who looked forward to visits with her son. These visits were able to occur due to her dear friend, Jerry, who brought Alex to Regent Care Center to visit.

As my position at Regent Care Center changed, I saw Ms. Gobrukovich less frequently, but when I did visit with her, she continued to speak about her son, Alex.

A great deal of Ms. Gobrukovich's quality of life centers around memories and continued visits with her son. Transfer of Alex to a facility a great distance away would be of great loss to Ms. Gobrukovich. Therefore, reconsideration on your part would be greatly appreciated.

Sincerely,

Jean Monnecka RN

Jean Monnecka, RN
Assistant Administrator
Patient Care Services

JM:MTS

HALLMARK NURSING CENTERS

52X

REGENT
CARE CENTER

50 Polifly Road
Hackensack, NJ 07601
201-646-1166
FAX: 201-487-3835

December 5, 1991

To Whom It May Concern:

Jean Gobrukovich has been a resident at Regent Care Center, a long term care facility, since her admission. Having gotten to know Mrs. Gobrukovich on both a professional and personal basis, I can attest to the love and concern she continues to have for her son, Alex. She will often vent her feelings of joy for the ability to continue to see him, even with her present living status. Due to their monthly visit, Gerry Ruane has continued a link of love between Alex and his mother. Alex also visits each holiday with his mom.

Mrs. Gobrukovich daily speaks of Alex and his special needs. These visits have improved the quality of her life while living in this nursing home. An aged person often suffers numerous losses, so it is important for her not to lose this close contact she has with her son. This is a loss that is not necessary and can be avoided.

In speaking for Mrs. Gobrukovich, I ask that allowances be made for Alex to continue to live locally to his mother's "home", for both of their wellbeings.

Sincerely,

Charlotte Catrillo
Assistant Administrator

CC:MTS

IMMACULATE CONCEPTION CHURCH
49 VREELAND AVENUE
HACKENSACK, NEW JERSEY 07601

December 6, 1991

To Whom It May Concern/ Hackensack, NJ

Mrs. Jean Gobrukovich, a resident at Regent Care Center, attends Mass that I celebrate there each Monday. I am certain it would be a great comfort to her if her son, Alex Gobrukovich, could be transferred to Totowa where he could be brought to visit her more frequently.

Sincerely,

Thomas F. Lynch

Rev. Thomas F. Lynch, Pastor

54 X

COUNTY OF BERGEN
BERGEN PINES COUNTY HOSPITAL
230 East Ridgewood Avenue • Paramus, NJ. 07652-4131
(201) 967 - 4000

William P. Schuber
County Executive

Edward M. Lewis
Executive Director

December 5, 1991

Jerry Ruane
100 Sunset Avenue
North Arlington, NJ 07031-5929

Re: Alex Gobruk Placement

To Whom It May Concern:

We have been notified that Alex Gobruk is to be admitted to the North Princeton Development Center on 12/17/91; this is a long awaited and much welcomed event.

We also understand that this is a reputable facility but, if in the future, an opening arises in the North Jersey area perhaps Alex and his relatives and friends may benefit from placement in this (North Jersey) area.

If we can be of any further assistance, please contact us. Thank you.

Sincerely,

Arthur Dinkel, ACSW
Social Worker

em

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55X

Court to decide if man requires state assistance

By Michele Drayton

Hudson County Legal Protective Services for the Elderly is seeking a court determination of whether a Bayonne man, who has been diagnosed as mildly retarded, is able to take care of himself or requires a guardian because of his mother's frail condition.

Testimony centering on Alex Gobruk, 40, who has lived most of his life in a Kennedy Boulevard apartment was heard yesterday before Judge Robert Tarleton, presiding judge of State Superior Court, Chancery Division. Neither Gobruk nor his mother was in court.

Frank Goia, director of HCLPSE, is seeking to show that Gobruk is mentally incompetent and requires a guardian under the auspices of the state Division of Developmental Disabilities, Bureau of Guardianship.

Goia said the DDD had denied Gobruk's application for services because of "inadequate proof" that he was retarded before the age of 22. But Gobruk's case may be re-examined because he has been receiving Supplemental Social Income on the basis that he is mentally retarded.

If he is determined ineligible for DDD services, Goia said, Gobruk could not be assisted by the county Association for Retarded Citizens.

Richard Seltzer, the attorney representing Gobruk, said his client's competency is "borderline" but did request a temporary guardian be appointed until it is determined whether Gobruk is eligible for services.

Dr. Jacob Jacoby testified via telephone that Gobruk is capable of basic functions but is mildly mentally retarded and needs assistance.

"I think he will need a structured environment (someone to help him make decisions, tell him what to do) forever," Jacoby said. He added he saw Gobruk last fall and performed psychiatric assessments in March and April.

Gobruk and his mother, an elderly woman most recently hospitalized for a broken hip, live in an apartment where tenants have complained about Gobruk's sometimes violent outbursts." Both lawyers said such outbursts have occurred.

The landlord received a judgment to evict the Gobruks but has not because of concern for them. Gobruk's income is a monthly SSI check.

"Everybody is in an ambivalent position. No one wants to see Alex hurt or imposed upon," Goia said. The tenants who have complained about Alex are the same people who helped him while his mother was hospitalized, he said.

Jerry Ruane, a family friend who lives in North Arlington but visits the Gobruks regularly, testified that Gobruk is capable of feeding and dressing himself but would need help in handling money matters. Ruane testified that he wrote out some of the bills while Gobruk's mother was hospitalized.

Ruane is among several people and agencies (Bayonne Office on Aging, ARC) who have taken an interest in the Gobruks.

"The concept of paying bills is not within his grasp," Ruane said. "Alex has amazed me with some of his 10-letter words (words) that are not in a six-year-old's vocabulary."

Ruane said he could not determine what kind of guardianship is needed but did not want to see Gobruk institutionalized.

Tarleton recommended that Goia investigate social services offered by churches to see if any could be provided for Gobruk. Seltzer is expected to have another doctor examine Gobruk.

Margo Caldy, of the DDD said it would "help in any way as long as there are no presumptions made around the eligibility issue."

In the meantime Ruane and representatives from ARC and the Bayonne Department of Health and Welfare will continue to check in on the Gobruks.

Police suspect arson of impounded Buick

Police said they suspect arson in a car fire Sunday morning in a municipal car pound that destroyed an impounded Buick.

The Bayonne Fire Department responded to the 2 a.m. fire with an engine company but could not get into the sealed pound. When the gates were opened, police found the vehicle completely burned out.

Melee on Broadway

Police said a Bayonne youth told them he smashed the window of a Broadway tailor shop with his fist by accident when he said he tried to defend himself Sunday morning from six assailants.

John R. Dito, 18, was treated in Bayonne Hospital for a cut to his right hand in the 2:30 a.m. incident, police said.

Police said they charged Ronald Carr, 19, of Jersey City with simple assault.

56X

T E S T I M O N Y

FOR THE APPROPRIATIONS COMMITTEE
of the New Jersey Assembly

December 11, 1991

by Harry Randall
12-58 Edward Street; Fair Lawn, NJ 07410
(201) 797-9332

Mr. Chairman and Members of the Committee:

I am Harry Randall of Fair Lawn, speaking for many families of people with mental retardation at North Jersey Developmental Center and other Developmental Centers. I aim to reflect their views, but I accept responsibility for my words here.

Some conclusions first:

1 - Closing the Johnstone Training and Research Center or any other Developmental Center in the foreseeable future is unconscionable, given the waiting list of retarded people with urgent needs, and given the lack of better or even appropriate alternative facilities for those now served in these centers.

2 - Simplistic programs have been advocated by some which ignore the important differences between those with mild or moderate retardation and those with severe or profound retardation or with multiple disabilities. Those with lesser retardation vastly outnumber those with greater disabilities, so the latter are easily neglected in planning. These with greater disabilities are the very ones that developmental centers increasingly serve, and can serve better than existing alternatives.

3 - Meeting arbitrary numbers goals is driving many transfers of clients, not improved life for the clients, in spite of lip service to the latter.

57X

4 - Some who should be advocates for all are following lop-sided and divisive dogma which fails to serve the most disabled clients, instead of serving the full range of needs and conditions through a full spectrum of different services. These dogmatists have erected an arbitrary dividing line between larger facilities and smaller ones, ignoring clients' differing needs.

5 - Services for people with Mental Retardation in New Jersey are vastly underfunded, and are deteriorating, whether they live at home, in group homes, in supervised apartments, in foster homes, or in Developmental Centers. New Jersey can afford much better, as the state with the second highest per capita income, in the country which claims the world's highest standard of living. It's up to you legislators, of whatever party, to fund these and other deteriorating human services and to give leadership in explaining the rightness of this to our fellow tax-payers.

6. Closing Developmental Centers will not save money for community services, in spite of claims to the contrary. It would simply transfer the higher costs for those who need the most care, while reducing their access to services.

Now to back up these conclusions.

We've heard some one-sided arguments for closing Developmental Centers, largely based on failure to recognize the range of disabilities and needs within the mental retardation spectrum--roughly classed as mild, moderate, severe and profound retardation. In addition, there are those with multiple disabilities such as epilepsy, blindness, paraplegia, autism, problem behaviors and chronic illness.

Some advocates have a tendency to generalize by portraying all people with retardation as matching Public Relations prototypes who can potentially ride a bus on their own, hold a job, learn in a classroom, prepare meals, and speak understandably to others. This by-passes those who can't walk, or can't talk, or can't dress themselves, or can't even feed themselves or take care of their toilet needs. Some can function only at a 6-year-old level, some like 4-year-olds, some like 2-year-olds, and a few like 6-month-olds. To speak, for instance, of their "right to take risks" is ridiculous! Would we want our normal 3 or 4-year olds to go shopping by bus on their own, or to cross a busy street alone? Levels of permissiveness and choice need to be governed by differences in functional levels.

In the opinion of many, including those of us in the Parents Associations of Developmental Centers, many clients with severe or profound mental retardation can be served best in larger facilities, where more direct care and central medical, nursing, speech therapy, physical therapy, behavior modification, and skill training can be provided with economies of size. At the same time they can take as much part in community living as people with these disabilities could experience anywhere.

As has been stated recently by various experts and care-givers, it isn't the size of the living facility that matters, but the adequacy and quality of the care provided.

We parents worry over long-range plans that endorse the closing of Johnstone as a prelude to closing all other Developmental Centers, as this would wipe out adequate support for the clients we're describing. Some who should know better

have jumped onto the pendulum of closing all larger facilities. I think they are blind in one eye.

We ask you to legislate for all retarded people according to their unfilled needs,--some of them desperate. All facilities suffer from underfunding, and all should be improved. Some no doubt shoud be replaced in time by better and different facilities,--when these are funded, built, staffed and tested.

Some years ago, group homes were launched on a growing scale,--and were supposed to be the coming answer tc the needs of people with retardation. Though not nearly enough have been established, they have been of benefit to many, unsuccessful for some, and an unsatisfactory facility for others who proved to manage better elsewhere--some in supervised apartments, for instance, and others back in Developmental Centers.

In my memory, services to people with mental retardation have always been underfunded in New Jersey, including Developmental Centers. Today the underfunding is much greater.

It is a false argument that we have two state systems to serve retarded people, and can afford only one and so must eliminate one. We have, and need, only one, with enough subdivisions to provide a spectrum of facilities to serve different needs in different ways. These include support for those living with families, independent living arrangements, supervised apartments, group homes, foster homes of several types, and Developmental Centers.

It is an artificial division to call some of these "community" and others "not community." Today's Developmental Centers are not the isolated, restrictive, custodial institutions of earlier years. My severely retarded daughter at North Jersey D. C. is taken regularly off campus to workshops, restaurants, and shopping. She visits other people's houses and has a lively, gregarious social life with parties, dances and Special Olympic athletics.

Some people point an accusing finger at Developmental Centers because, despite the marked reduction of their population, per capita costs have risen. But note that the population of these Centers has come to consist more and more of those with the greatest disabilities, who need the greatest care and the largest direct-care staffs. So the increase in average per capita cost was inevitable.

Assuming that enough adequate small facilities will be established for those who can actually live better in them, when such clients are transferred out the Center population can expect to consist entirely of those with profound retardation or multiple disabilities. And the per capita cost will understandably go higher yet. But wherever these most fragile people live or move, the higher cost of care will move with them--unless they are shuttled off into inappropriate foster homes with poor care or neglect.

Very few group homes exist that are tailored to the needs of multiply-disabled clients, or those with behavior problems. In these few, the costs of staffing and services hve proven considerably higher. I'm told that one ARC group home is no

longer accepting those with the behavior problems it was originally designed to serve. Where, then?

We are told by several experienced people who have investigated costs that care in group homes proves to be just about the same as in the Centers. So cost is ruled out as a legitimate argument for moving people from Centers to group homes. That leaves the really valid measuring stick of quality of life. For some of those who now live in the Centers, life could be improved in a group home. For others, not so. This will vary greatly with individual conditions and needs.

Moving is one of the most traumatic events in anyone's life. This is at least as true for people with severe disabilities. So transfers should be planned to meet real needs, and with the prospect of real improvement before people are moved, and not for dogmatic or political motives, or to suit an arbitrary numbers game.

Most emphatically, we deplore the rush to promote cheap "skill-development" foster homes to house many people moving from Developmental Centers, concurrent with the influx of clients transferred from Johnstone. This reliance on skill-development homes is to us an unsatisfactory substitute for the group homes which are lacking, and where many of these clients could have been more adequately placed.

Such homes were introduced to us a few years ago with the explanation that they were to provide a relatively short period of social adjustment and behavior modification by trained experts to prepare a few selected clients for living in a group home.

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Now their function and purpose has evidently changed to a long-term ~~inexpensive~~ cost-cutting arrangement for many. This appears to be another case of expediency and budget determining policy, rather than designing policy to serve clients. And numbers again appear to be determining how many and who will be placed in these foster homes, rather than their suitability for individual needs.

We worry about our sons and daughters ~~going~~ being sent to these foster homes, because we see a lack of truly adequate training for handling their needs, a lack of adequate frequent supervision and inspection (claims to the contrary notwithstanding), and the lack of enough staff to "blow the whistle" in case of cruelty or abuse, which are known to occur too often in foster homes.

We call on you to appropriate enough funds to establish the group homes and other community services that are needed, and to aupport and fund all Developmental Centers for those who will long continue to need their special services.

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13

SAVE JOHNSTONE TRAINING & RESEARCH CENTER

By Donald L. Klein, M.S.

It was just thirty (30) short years ago that Johnstone Training and Research Center was recognized nation-wide as a prestigious facility dedicated not only to the daily care of the mentally retarded, but to future client needs, through its research and development components. As well, the same applied to its sister institution, the New Jersey Neuro-Psychiatric Institute at Skillman, then dedicated to the care of the mentally ill. These facilities each published more than twenty-five (25) professional papers per year. Highly trained professionals provided top quality services for clients. Pride in achievement was the hallmark. These facilities continue to have highly trained professionals and dedicated staff, despite the interference by State officials.

State officials, for over thirty (30) years have abandoned the mentally ill and developmentally disabled. Institutional buildings constructed by artisans have been sinfully left to decay. Throngs of brilliant social scientists have long disappeared from the campuses, leaving a skeleton staff of dedicated professionals. It is evident that recent administrations don't care about the State's most vulnerable citizens, they only care about their own political careers and are blinded by dollar signs. There is money for their

64X

State offices, far removed from client cottages.

Due to the State's unforgivable neglect, they are now evicting patients from their homes. Homes that blind and mentally retarded clients have taken many years to become accustomed to. The State is ripping apart long established friendships. Some patients have no families, their family are peers and staff. Life changes are difficult for so-called normals, however, changes for developmentally disabled individuals are devastating.

The first to be impacted by budget deficits are those with no voice. Guarantees to maintain vital public services only appear during political campaigns.

Commissioner Alan Gibbs and Robert Nicholas, Director, Division of Developmental Disabilities have betrayed Johnstone clients, staff and their respective families. These state officials have subjected developmentally disabled citizens to what amounts to be psychological abuse. These are the same individuals who have supposedly been entrusted to protect their rights. Robert Nicholas publicly stated that non-accredited units at existing facilities could have been phased out rather the full closure of Johnstone Training Research Center. They mistakenly opted for the latter alternative which has resulted in utter chaos in so many lives.

The 1992 DHS proposed budget cites overcrowding at North Princeton Developmental Center, where Johnstone clients are slotted for transfer. Additional placement changes are necessary and a clear possibility exists that Johnstone clients will be again displaced.

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This committee cannot undo the pain that has already been inflicted, however, it is not too late to prevent a tragedy, the closure of Johnstone Training and Research Center.

December 10, 1991

TESTIMONY OF COLLEEN L. FRASER, CHAIRWOMAN,
NEW JERSEY DEVELOPMENTAL DISABILITIES COUNCIL,
TO THE ASSEMBLY APPROPRIATIONS COMMITTEE

December 11, 1991

This hearing is an affront to every person with a developmental disability in New Jersey.

It has serious and needlessly damaging consequences for the people with developmental disabilities affected by it. It creates the impression that the decision to close Johnstone can be overturned. That raises false hopes in those who still oppose it, raises needless anxieties in the minds of those intimately involved in the closing--the people who live at Johnstone and the people who are helping them prepare for better lives elsewhere, and reopens a conflict that has badly divided the state's developmental disabilities community just when the wounds of that conflict were beginning to heal.

The Developmental Disabilities Council is federally mandated to advise the State legislature, the Governor and the public on policies which affect people with developmental disabilities. As such, the Council is bound to protest the harm this hearing may cause.

The public debate over closing Johnstone was settled last summer. In that debate, every responsible voice agreed with the Division of Developmental Disabilities, the Department of Human Services, the Governor and the State Senate that Johnstone should close.

The Association of Retarded Citizens of New Jersey agreed. The overwhelming majority of its ten thousand members are parents of people with mental retardation. The New Jersey Developmental Disabilities Council agreed. The majority of its members are people with developmental disabilities and their families. Half a dozen other statewide organizations that serve people with developmental disabilities or plan and deliver other human services agreed.

The process of closing Johnstone is well under way. The Division's plan for closing it has been updated and reviewed by all interested parties and submitted to the State legislature. An extensive process for monitoring that plan is in place and being aggressively implemented.

More importantly, 40 people have already left Johnstone for better lives than they lived there. They know it and their families know it. No one has objected to any of these placements or taken any action to appose any of them.

(more)

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COLLEEN L. FRASER, CHAIRWOMAN,
N.J. DEVELOPMENTAL DISABILITIES COUNCIL

add/1

This hearing diverts energy and attention from the important tasks of monitoring the closing of Johnstone to make sure that every person affected by it will live a better life and providing support to them and their families during their transition to that better life.

It diverts all of us from the unfinished business raised by the State's decision to close Johnstone in the first place. That decision was driven by the recognition that New Jersey's system of care for people with developmental disabilities is in need of major reform.

The ten large institutions the Division runs form the decaying center-piece of that system. They were built to serve 9,000 people. They now serve less than 5,000, at least 1,500 of whom have been determined able to live in the community. A system built to serve 9,000 people cannot be sustained unchanged to serve less than 3,500.

Change must occur. That change must protect the people with developmental disabilities who we do not have the wisdom, knowledge or will to serve adequately in the community. That change must acknowledge the legitimate needs of the people working in that antiquated system. That change must recognize the legitimate claims of other people with developmental disabilities who are denied services today because resources are lacking to serve them.

That change requires hard decisions, hard thinking and hard work. It requires the best in all of us.

The Council calls on all responsible members of the developmental disabilities community to move beyond the divisiveness this hearing fosters and concentrate on the difficult but constructive tasks that now confront us.

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(For more information, contact the N.J. Developmental Disabilities Council, (609) 292-3745.)

68X

New Jersey
Day Training Coalition

ASSEMBLY APPROPRIATIONS COMMITTEE
WEDNESDAY, DECEMBER 11, 1991
PUBLIC HEARING
Testimony of Denise Walker

Members of the Assembly Appropriations Committee, as President of **New Jersey Day Training Coalition (NJDTC)**, I want to thank you for allowing me to testify today.

NJDTC represents children with severe and profound developmental disabilities currently classified as **Eligible for Day Training**. These 1,033 pupils attend the 18 state operated day training centers, and approximately four contracted day training center programs. Our membership is made up primarily of parents. We promote the active and informed participation of parents in caring for and supporting their children at home, in their neighborhoods, and communities, and particularly in shaping, implementing, and evaluating public and educational policy which affects them.

Our goals are not for our children to grow up, leave us, and go to an institution. As parents, we envision our children in the community setting.

At this point, as a group, we feel that the monies spent on running Johnstone and the monies required to repair the building to code, should be spent on good solid community based programs and homes. We feel it is time to stop repairing the wheel and build a new one with spokes in the community.

As parents of children whom we have consistantly decided to keep home, we need to rely on the support of the community and the Division of Developmental Disabilities. At this point we feel that we habitually are being asked to give up bits and pieces of the small amount of support available to us. If we do not look towards the future and the conscionable approach to our children and their families, we will find ourselves facing the institutionalisation of many more clients and the breakdown of families no longer able to function.

Thank you once again for this time to listen to my testimony.

Sincerely,

Denise Walker

Denise Walker
President

22 Washington Avenue • Rumson, New Jersey 07760 • (908) 747-5950

69X

UNITED CEREBRAL PALSY
OF MONMOUTH & OCEAN COUNTIES, INC.
1111 Green Grove Road
Neptune, New Jersey 07753

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EXECUTIVE DIRECTOR
Anita M. Kneeley

Appropriations Committee of the Legislature

Thank you for the opportunity to speak to you today concerning the outdated institutionalization of many people with disabilities.

United Cerebral Palsy of Monmouth and Ocean Counties, Inc. is deeply involved in ensuring an array of options for people with significant and multiple disabilities. Many of the people we serve have traditionally being served in institutions, the erroneous perception that all people with physical disabilities are in need of medical attention, and the lack of properly trained personal care assistants to permit these people to live within the community. We recognize that the array of options required includes Group Homes, supervised residence, supported living, foster placement, respite, and personal care assistants, transportation, and for a small number, medically oriented options facilities. There may even be a few people who are best served through what is labelled a developmental center.

Agencies like United Cerebral Palsy of Monmouth and Ocean Counties, Inc. provide valuable service to assist the State of New Jersey to meet its responsibilities. We subsidize the State in several ways. Our staff earns less, on average, than comparable State employees; we do not have access to the expansive and expensive array of subsidized benefits, including pension, vacation, holidays, and especially health, dental and prescription plans. We fund raise to close the gap between the cost of services we provide and the reimbursement provided by State contracts. We have been forced to hold the cost of these programs to the State at a fixed ceiling for at least three years. We anticipate little or no budget relief in the u-coming year. We recognize that the only way that we and New Jersey, as partners in meeting the needs of the people we serve, can continue to fund essential services, is to seek dramatic ways to consolidate necessary services and to eliminate less essential services. Hiring freezes, budget freezes, and denial of cost-of-living increments deny safety and dignity to the people we serve. Only by closing down

70X

and consolidating under-utilized or underfunded programs can we ensure that the necessary programs and locations are assured adequate resources. In Developmental Disabilities, in Mental Health, and indeed in the Department of Health, we cannot afford redundancy.

Johnstone Training Center has done its job. The residents are ready to move on - to the community; to other, identified, properly staffed locations. Let us salute the good people who have made this possible, and let us move on.

Thank you.

Anita M. Kneeley
Executive Director

AMK:jw
12/11/91

71X

United Cerebral Palsy of Mercer County, Inc.

1670 WHITEHORSE-HAMILTON SQUARE ROAD • SUITE 2C • HAMILTON, NJ 08690-3506
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KEVIN L. LILLY, ESQ.
President

WENDY P. CROOK, MSW
Executive Director

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Serving people with disabilities and their families.

December 12, 1991

Assemblyman John Watson
224 West State Street
Trenton, NJ 08608

Dear Assemblyman Watson:

Please accept this letter as written testimony regarding the closure of Johnstone Developmental Center.

Our organization was formed four years ago to provide community-based, integrated services for people with disabilities and their families. In that short time, over 300 such people have received services through our agency, and countless more have come to our attention as needing services. We feel strongly that people with disabilities can best be served by assisting them in finding and retaining homes in the community.

In a recent legislative forum sponsored by our agency and ARC Mercer, you stated that Johnstone was a "community-based program". We couldn't disagree more. Johnstone is an institution. It segregates people from society. It serves to perpetuate the notion that people with disabilities deserve to be kept separate from the rest of the population, both for their safety and that of the public. It negates the fact that people with disabilities have individualized needs, interests, capabilities, wants and desires.

We feel that the Johnstone closure provides individualized plans for each person, and offers true community-based alternatives for those ready to live in real homes. I have personally worked for the last ten years to bring people out of institutions, and have witnessed the tremendous growth, realized potential, and contribution of people once they live in the community. Also, I have seen many parents who

72X

were fearful for their grown children's safety outside of the institution become supportive once they observed their sons' and daughters' success in the community. I am confident that once the Johnstone parents experience their children's move to the community as an accomplishment such positive feelings will result.

We feel strongly that it is time for New Jersey to make a real commitment to its citizens with disabilities. The funds required to keep an institution like Johnstone open are desperately needed in the community by families struggling to maintain their members with disabilities in the home, and by those people currently living in institutions who desire to live in a real home.

We respectfully urge you and your colleagues to make a bold move now, to close Johnstone, and to make a commitment to citizens with disabilities who only wish to live in a home like yours and mine.

Sincerely yours,

Wendy P. Crook, MSW
Executive Director

DISABLED AMERICAN VETERANS

CHAPTER NO. 32 8 VETERANS PLAZA, BERGENFIELD, N. J. 07621
AREA CODE (201) 384-0011

December 6, 1991

Office of Legislative Services
Public Hearing Committee
Room 8
135 W. ~~Hanover St~~
Trenton, N.J. 08625

Dear Assemblyman Watson:

As a Disabled Veteran, I want to protest the closing of Johnstone. There is a waiting list of 4000 for their facility already.

The closing of Johnstone will worsen this situation. I look forward to hearing from yr. Sincerely,

Matt ~~Ford~~, M.P.A.
Judge Advocate Chapter 3:

74X