

To Boldly Go...

Individualized Supports for Georgians With Severe Disabilities

Prepared for

The Georgia Governor's Council on Developmental Disabilities

by

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July 1992

I want ...(whoosh) to cancel ...(whoosh) the DNR order. Those were the words Miranda spoke today. It took a while for her to get the sentence out because of the time it takes for the ventilator to fill her lungs. I listened as she and her doctor casually chatted about her decision to live. You see, "DNR" means "Do not resuscitate." It means, "If my heart stops, let me go –no heroic measures."...

My friend, Valencia, and I sat there not quite believing our ears. Neither one of us knew that Miranda wanted to die. She's only 36 years old. She doesn't have terminal illness and she's not in severe pain, at least not physically... After the doctor left, I asked, "Woman, you had a DNR order? Why?"

"No reason... to live ...'til now." ...

The promise of a different life changed Miranda's mind. With some help –both paid and voluntary– she will have a regular life.

from Pat Puckett, What a Day!

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List of Acronyms

AARP – American Association of Retired Persons
ACIL – Atlanta Center for Independent Living
ADA – Americans with Disabilities Act
ADAPT – American Disabled for Attendant Programs Today
CA – Citizen Advocacy
CCD– Consortium for Citizens with Disabilities
CCSP – Community Care Services Program
CHAMPUS – A health insurance provider
CSLA – Community Supported Living Arrangements
DD – Developmental Disabilities
DD Council – Georgia Governor’s Council on Developmental Disabilities
DFACS – Department of Family and Children Services
DHR – Department of Human Resources
DMA – Department of Medical Assistance
DNR – “Do Not Resuscitate”
DRS – Division of Rehabilitation Services
GRC – Georgia Retardation Center
HCFA – Health Care Finance Administration
LADD, INC. – Clayton County Supported Living Organization
LPN – Licensed Practical Nurse
NPR – National Public Radio
OBRA – Omnibus Reconciliation Act
OT – Occupational Therapy
PT – Physical Therapy
VR – Vocational Rehabilitation
VRU – Vocational Rehabilitation Unit at Warm Springs

Summary

This study examines Georgia's long term support services from the point of view of the achievements and aspirations of eleven people with severe disabilities and their families and friends. Their situation underlines the need for systematic redesign of the present system, which is currently dominated by public investment in nursing home beds.

Georgia nursing home operators consider four of these people's needs to be impossible for them to meet because they use ventilators to breathe.* This leaves them with the apparent choice of living in a hospital at great public expense or living in a facility out of state. The other seven people could or do live in one of Georgia's nursing homes or institutions, but would not choose to do so unless they have no alternative.

A combination of personal and family resources, vigorous and skillful advocacy, and imaginative individualized service development now provides seven of these people with support to live in a way that increases their personal autonomy and supports them to participate in community life. This includes three of the four people the system has found impossible to place and plans for the fourth person's move to her own home are underway.

Each of these pioneering individualized support systems is vulnerable because Georgia's long term care system is dominated by policies and patterns of expenditure which assume that nursing homes are the necessary, desirable, and exclusive response to severely disabled people whose families and friends are unable to provide most of the assistance they need. The eleven people whose experiences inform this study challenge this assumption: *none of them wants to live in a nursing home and none of them needs to live in a nursing home* as long as the system does not deprive them of the specific assistance they need to live as they choose.

In challenging nursing homes as the exclusive providers of publicly funded, intensive long term care, these eleven people join their voices with those of thousands of other people with disabilities. Such diverse groups as Disabled Persons International, the American Association of Retired Persons, ADAPT, and the Consortium for Citizens with Disabilities (a coalition of 70 national advocacy groups) now advocate for much greater public investment in individualized support.

Long Range Objective

Georgia's long term care system offers all people, regardless of disability, a **real choice** between individualized support and nursing home, hospital or institutional care.

* One of these people, who now lives in a supported living situation, no longer uses a ventilator.

What Georgia Needs to Develop In Order to Offer People A Real Choice

Individualized support which offers people the help they need...

- ...to pay for and arrange necessary personal assistance services
- ...to find, modify, and maintain suitable housing
- ...to choose to benefit from good health care
- ...to choose to benefit from adaptive technologies
- ...to travel from place to place
- ...to plan, advocate, and arrange, necessary supports and to solve problems to maintain and improve them

with this support, people can pursue their own life choices concerning...

- ...occupation
- ...education
- ...personal relationships
- ...involvement in civic life

Individualized support allows costs to be shared among public agencies and with the person receiving support and the person's family and friends.

Because individualized support is specific to the needs, resources, and circumstances of each person, administrative flexibility in managing a diverse and changing system is crucial.

Individualized support offers an alternative to everyone now in a nursing home, regardless of the cause of their disability. People who are severely disabled as a consequence of aging and people with cognitive and emotional disabilities can benefit from individualized support as much as younger people with physical disabilities can.

Individualized support presents the person receiving support with a different mix of risks than nursing home care does. A person who chooses individualized supports trades immediate access to nursing care and a professionally managed lifestyle within a specifically adapted building for greater choice and autonomy in a community environment that may not be entirely accessible, accepting, or supportive.

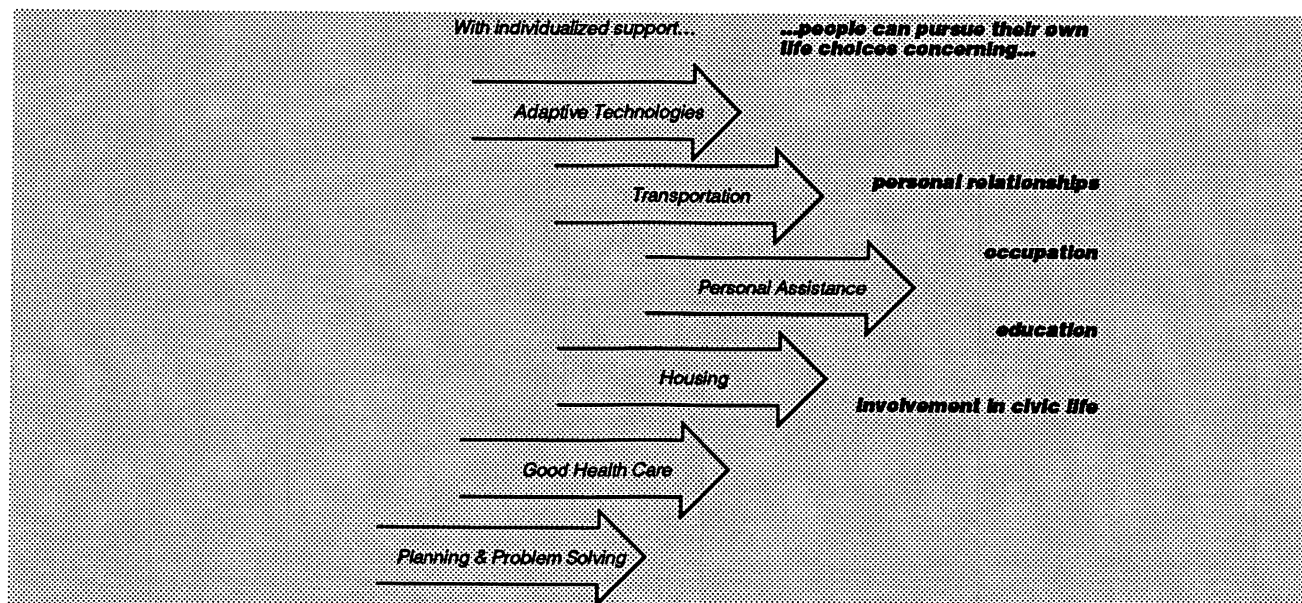
The most important policy change must be to increase the amount and quality of personal assistance services.

Personal assistance services (PAS) mean one or more people assisting another person with tasks which that person would do if not disabled. PAS include performing such tasks as...

- Dressing, bathing, eating, using the toilet (including bowel, bladder, and catheter assistance), getting in and out of bed or wheelchair, and ordinary assistance with breathing equipment
- On the job assistance
- Shopping, cooking, and cleaning house.
- Driving and routine vehicle maintenance
- Cognitive assistance with planning the day, maintaining routines, managing money, etc.
- Assistance with communication through interpreting and reading

Priorities for action

- Policies and public expenditure on personal assistance services are the least developed system resources necessary to insure the development of a long term care system that offers people a genuine alternative to nursing home care.
- Individualized supports are a real alternative to current policies (apart from the Independent Care Waiver), not just an add-on to the present system. Individualized supports embody different ways of thinking about people with disabilities, different sorts of organizational designs, job roles and procedures, and different kinds of management. Effective and sufficient personal assistance services cannot develop without vigorous advocacy and strong agency leadership to overcome the biases which have accumulated in the present system.
- Policies and public investments in affordable, accessible housing will benefit a number of people who need individualized supports.
- More people need opportunities to join people with disabilities and their families to plan and implement individualized supports and to develop local agencies with the capacity to provide assistance. Current efforts by Creative Pathways, LADD of Metropolitan Atlanta, and Georgia Options provide a beginning. Their work needs encouragement and assistance to allow people in other parts of the state to learn from them. Others with different ideas of how to organize individualized supports need opportunities to try.
- Given information about alternatives and a chance for change, it is likely that a substantial number of people now in nursing homes and hospitals would choose individualized supports. Independent efforts to reach-in to nursing homes need development.
- Well organized advocacy by people with disabilities themselves is vital to developing an effective long term care system. Organizing work by Shepherd Spinal Center, Georgia ADAPT, and Concrete Change provide an important beginning. Many people with severe disabilities are unable to join advocacy efforts because the current system traps them at home or confines them in nursing homes.
- Current development of individualized supports results from an international movement among people with disabilities and a parallel set of state and national initiatives by policy makers and service providers concerned to make effective use of public funds. Efforts to re-design Georgia's system will benefit from strong links with others working along similar lines.



Acknowledgments

Many people helped me to learn about this vital area of concern. I am grateful to...

- ...the people who welcomed me into their homes and shared their experiences and their ideas about a better future for themselves and other Georgians with disabilities. In particular, Jenny and Sheryl Langley generously shared their story with one more person who wanted to learn from them and I appreciate it.
- ...Pat Puckett and Mark Johnson, who acted as my guides to the network of people who are changing Georgia's system by changing their own lives and added to their already heavy workload to insure that there was broad participation in the Macon meeting that helped to focus the action implications of this study
- ...Martha Gilmer, whose initiative and concern led me to meet and learn from people in South Georgia
- ...the staff of the Department of Medical Assistance, especially Deputy Commissioner Gary Redding, for their openness and interest in the issues of providing better individual support.
- ...Lee Ann Pendergrass, Independent Living Coordinator for the Department of Rehabilitative Services, and Jonathan Kirkpatrick, of LADD, who offered their perspectives on how Georgia's system must develop
- ...Father Victor Frederiksen of Christ Church, Macon and the staff of Macon-Bibb Citizen Advocacy who helped with arrangements for the Macon meeting
- ...the Georgia Governor's Council on Developmental Disabilities for supporting the study as it developed and making it possible for many people with disabilities to attend the Macon meeting.

Introduction

This project began with a limited focus.

Jenny Langley, her family, friends, and allies made headlines by creating a real life alternative to a bed in a nursing home or hospital. For a year, Shepherd Spinal Center had flexibly financed Jenny's individualized supports and assistance at home using a portion of their Indigent Care Trust Funds. Then crisis struck. A five month lapse in funding between the end of Shepherd's obligation and the implementation of a new Independent Care Waiver threatened Jenny with re-hospitalization or placement out-of-state in a nursing home. Advocates and state officials sought alternatives. The Georgia Governor's Council on Developmental Disabilities and the Division of Rehabilitation Services provided money to bridge the funding gap. The Council made an important contribution to re-defining options within Georgia's system of long term care when it supported this innovation by temporarily funding Jenny's living arrangement.

The Executive Committee, and the Executive Director of the DD Council, decided that Jenny's situation provided an opportunity to gain a better understanding of state and federal long term care policy. Analysis of a Council supported policy innovation would help refine Council priorities for 1993.

The original brief for this study was to...

- Describe Jenny Langley's situation and her move from Shepherd Spinal Center to her own home.
- Investigate the Indigent Care Trust Fund. What is it? Who can use it? What can it pay for?
- Review and analyze state and federal laws and regulations that relate to Jenny's experience. What helps? What gets in the way?
- Make recommendations for Council action based on the descriptions, reviews, and analysis.

From the moment I started interviewing people and gathering information, it was clear that there was a lot of positive activity underway that didn't begin and end with Jenny but was closely linked to her and her allies. I decided that my analysis and recommendations for the project would be enriched if situated in a broader context. My initial meeting with Jenny immediately

introduced more people to the study. Jenny showed me a newspaper article featuring her and Miranda Ivey, who was (and still is) living in a hospital because of the lack of alternatives. Miranda's dream for herself and Jenny's support for her was compelling. Jenny also spoke about Charles Lewis and Charlie Grier, two men who had recently moved from Grady Hospital to a house in Atlanta. Grady was using Indigent Care Trust Funds to pay for their supports. I decided I wanted to meet them.

Then Zebe Schmitt received a letter from Martha Gilmer with Home Care Services in Jesup. Martha was concerned about three men from her area who were not getting enough support and were at immediate risk of going into a nursing home. Zebe asked if I would talk with them since their situation seemed to fit so clearly with this project. That's how I met Larry Allen, Shane Barrow, and Wayne DeLoach.

When I met Lee Ann Pendergrass, Coordinator of the Independent Living Program in the Division of Rehabilitation Services, I learned that the group home in Augusta where Larry McAfee lives had been established with Indigent Care Trust funds. Tony Cordova had lived in this group home, but he had moved into his own apartment after Larry, to whom the initial offer was made, turned it down. Talking with Tony seemed too important an opportunity to miss. He had multiple experiences (living for years with family providing all support, as well as in a group home and most recently in his own apartment) to share.

Fred Pinson attended a workshop I led in May. His expenses and attendant care were paid by the Georgia Advocacy Office because he is on the board of the Dekalb Citizen Advocacy Program. He told me about living in a nursing home in Snellville and wanting to get out. Fred later called me to ask if I would write a letter to help him get a waiver from the limited number of nights he could be absent from the nursing home without losing his place. I found that Zebe Schmitt had written a similar letter for Fred when he had to be away from the nursing home to attend a meeting of the State Special Education Advisory Committee of which he is a member. Fred's situation seemed important to the story.

As I interviewed people who work for the Department of Human Resources and the Department of Medical Assistance, I learned of Gary Foss in Savannah who has been trying for years to get out

of a nursing home and Megan Knight, a young child at Brook Run, whose mother wants to find a way to bring her home. I didn't meet Gary or Megan in person, but I talked to Gary's citizen advocate and two people who currently support him, and I talked with Marsha Knight, Megan's mother.

As I met people as individuals, it became important to have a meeting where anyone who had participated in the project could get together to meet each other and to discuss the project findings and recommendations. The people I met have a lot to offer each other, but some have never been connected to any organized group concerned with disability issues and have never met state officials whose decisions influence their lives. Having a gathering could allow several important things to happen at once.

From organizing this meeting, I probably learned as much about the difficulties that people with severe disabilities face on a daily basis as from anything I have ever done. Just finding a place that was genuinely accessible and could accommodate eight or ten people who use power chairs almost ended the notion of having a meeting. Lack of transportation. Lack of personal assistance. Lack of money to pay for personal assistance that might be available. The meeting did happen, though—in Macon at Christ Church on Monday, June 22. I expected twenty-five people. Fifty people, including three who use ventilators, came. Mark Johnson noted, "This may be the largest group of people with ventilators ever gathered together in Georgia outside of a hospital!"

Much about the Georgia system's way of doing things must change. But there is much about the ways Georgia people respond to the challenges of severe disability that we should honor and preserve. I discovered strong and effective informal links among people who, little by little, are changing the way people with disabilities can live in Georgia. And I found the system supporting change for a few of these people—not enough, with too little money, and certainly nowhere near fast enough!

I have Tony Cordova to thank for the title, *To Boldly Go...* When Pat Puckett and I visited Tony, he gave me some of the material he uses in his work with other people with disabilities. There was an article from *Mainstream* (Nov. 1991) that describes ADAPT's action at the annual meeting of the American Health Care Association in Orlando. A picture shows the back view of a

person in a wheelchair with a large sign which reads, *To Boldly Go Where Everybody Else Has Gone Before*. All the people I met are boldly trying to go this way, but there are lots of obstacles in their way. It's hard work, and less because of the person's disability than because of ineffective policies, outmoded programs, and mis-allocated public resources.

As I worked on this study, a twist on the phrase became relevant to me. If people with disabilities are willing to risk by boldly going where everybody else has gone before, people in leadership positions must be willing *To Boldly Go Where No One Has Gone Before*.

Together, we must boldly attempt to change old patterns of service that sentence people to facilities (Both Miranda and Tony talk and write about feeling sentenced like a criminal to a prison for having committed no crime except for having a disability). Together, we must boldly speak out in support of and with people with disabilities when funding sources limit what people want for a decent life. Together, we must boldly attempt some things we're not quite sure how to accomplish, because that is the only way to learn what we must know. Together we must boldly support and confront each other as we try to learn our way out of nursing homes, institutions, and hospitals. In this way, people with disabilities will have an ordinary choice *To Boldly Go Where Everybody Else Has Gone Before*.

Overview

In this report I will...

- **Briefly introduce the 11 people whose situations inform the report.**
- **Outline my perspective on the strategic issues in Georgia's long term care system.**
- **Identify the need for Georgians with severe disabilities to have a real choice between individualized supports and care in a nursing home, hospital, or institution.**
- **Introduce the contributions Jenny Langley and her family are making to changing the system.**
- **Describe the variety of commitments from family members, friends, allies, and service providers necessary for successful implementation of individualized supports.**
- **Briefly analyze current long term support policies, sketch a possible scenario for system development, and identify the two most critical resources necessary to support development: more effective personal assistance services and a unique blend of personal and systems advocacy and problem solving.**
- **Make recommendations to the Governor's Council on Developmental Disabilities.**

The People

These people's experiences inform this report. I met or learned of their situations between March 17, 1992 and June 22, 1992.

Jenny Langley: Jenny was the original focus of the study because the DD Council assisted her to establish her individualized support system. Shepherd Spinal Center supported Jenny's move from Shepherd to her own home, and paid for home modifications, and

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personal assistance using money from Shepherd's Indigent Care Trust Fund. Shepherd's financial support was limited to one year. LADD, Inc. is the community agency that handles administration and finances for Jenny. I first met her at her home in Jonesboro where she lives with her sister, Sheryl, her brother-in-law, Joe, and her two nieces, Jackie and Jesse. Jenny was doing

well, but there were problems finding money to continue her support when Shepherd's obligation ended. Jenny is the first person supported by the Independent Care Waiver. Problems are still being resolved about whether or not immediate family members like Sheryl can be paid for the support they provide for a family member. Jenny and Sheryl were at the Macon meeting.

Charles Lewis: Charles moved into his home in Atlanta in September, 1991 after living at Grady Hospital for more than three years. He lives with Charlie Grier, Dan Danner, and Martyn and Lesa Hope. Other people come in to provide additional support. Grady Hospital financed this living arrangement for Charles for one year out of its Indigent Care Trust Fund. Charles expects to be supported by the Independent Care Waiver when funding from Grady ends. LADD is the community agency that handles administration and finances for Charles. Charles was in the hospital at Shepherd Spinal Center when I visited in his home. I have not met him in person. As of June 22, Charles was back home. He wanted to come to the Macon meeting, but he was still convalescing.

Charlie Grier: Charlie moved into his home in Atlanta in September, 1991 after living at Grady Hospital for more than three years. He lives with Charles Lewis, Dan Danner, and Martyn and Lesa Hope. Other people come in to provide additional support. Grady Hospital financed this living arrangement for Charlie for one year out of its Indigent Care Trust Fund. Charlie expects to be sup-

ported by the Independent Care Waiver when funding from Grady ends. LADD is the community agency that handles administration and finances for Charles. I had lunch with Charlie, Dan, Martyn and Lesa and spent time talking with them about their situation. Charlie came to the meeting in Macon with Dan and Martyn.

Tony Cordova: Tony moved into his apartment in October, 1991. He'd been working toward this goal since his automobile accident in 1979. For eleven years Tony's family (first his mother in Colorado and then his sister in Augusta) took responsibility for meeting his basic needs. Tony lived for a year in a group home in Augusta that was funded by Indigent Care Trust Funds from the Medical College of Georgia. When Larry McAfee, the man whose situation was the impetus for the group home, was offered the opportunity to move out of the group home into his own apartment, he turned it down. Tony did not hesitate when the same offer was made to him. He just wishes the opportunity had come sooner. Tony hires, fires, supervises his own attendants. The major problem right now he faces is where is the money going to come from once the Indigent Care Trust Funds stop?

Larry Allen: Larry lives in Jesup, Georgia. I met him at his home on March 31, 1992. He was living with his mother. Larry has been in and out of hospitals and nursing homes since a diving accident in 1984 resulted in his being paralyzed. His mother, his primary caretaker, recently had a stroke resulting in Larry again spending time in a nursing home. Although he was home at the time of my visit, he and his mother anticipate that without additional support he will be again forced into a nursing home. Martha Gilmer with Home Health in Jesup contacted Zebe Schmitt about her fear that Larry is not eligible to receive enough assistance to stay home which is what both he and his mother want. I tried to contact Larry again by phone after March 31 and never got an answer. I mailed him a summary of my visit and an invitation to the Macon meeting. I received no response. Larry may now be in a nursing home.

Shane Barrow: Shane, an eighteen-year old high school student, lives in Hagan, Georgia with his mother, a single parent. I met them on March 31. Shane was injured in a diving accident in September, 1991. He spent several months at Shepherd Spinal Center

where he and his mother learned to care for his personal needs. Mrs. Barrow was forced to quit her job to stay home and support Shane. They currently live on Shane's SSI payment of \$422/month. Shane returned to school in April and attended until he had an operation for kidney stones just before the end of term. Shane wants to complete his high school education and go to college at Georgia Southern. Shane and his mother receive very little paid support. The support he does get is Home Health (he became technically ineligible since returning to school because Home Health requires that a person be "homebound"), and the CCSP program, which might offer some support, has a waiting list of 189 people. Shane and Mrs. Barrow came to the meeting in Macon.

Wayne DeLoach: Wayne was injured in January, 1990, in an automobile accident which resulted in his quadriplegia. After being released from Roosevelt Warm Springs hospital, Wayne lived just outside Statesboro with his sister, brother-in-law, and their two children. Wayne is passionate about being independent. He hates the idea of having to ask for help or adding to his sister's already busy, hectic life. I met Wayne on March 31 after Martha Gilmer wrote of her concern that Wayne would end up in a nursing home because he was not getting enough support at home. Wayne was spending as many as eight hours a day at home alone. He had several accidents falling out of his wheel-chair and being unable to get back in or up until family members arrived home after work. The only support available was the Home Health Services which required that he be "homebound." Wayne was still receiving these supports even though his attending Alcoholics Anonymous (AA) meetings officially made him ineligible. There are 189 people ahead of Wayne on the waiting list for CCSP. Wayne was very excited about the Macon meeting. He had convinced his mother and two aunts to accompany him. Wayne died on Friday, June 19 three days before the meeting.

Fred Pinson: Fred is a thirty year old man who was born with cerebral palsy. He lived at home with his family until he was twenty-two and became too heavy for his parents to continue his care. His parents tried to find a suitable alternative living arrangement for Fred, but the only place they could find was a nursing home. Fred continues to live in a nursing home in Snellville although he would prefer to live in his own place with the personal assistance

he needs 24-hours per day. Fred is puzzled by the fact that no one ever talked to him during the OBRA (Omnibus Reconciliation Act) assessments that supposedly were to ask people if they preferred to remain in the nursing home or have supports to live elsewhere. Fred's parents are still intimately involved with Fred. Fred met Charles and Linda Mingle about seven years ago when they became his citizen advocates. Fred is the current president of the Dekalb Citizen Advocacy Office. He also serves on the State Special Education Advisory Committee. These are honors for which he must pay dearly. He fights a constant battle not to lose his place in the nursing home because his obligations require overnight stays away from the nursing home. So far, his requests for waivers to extend the number of nights he can be away have been won with great effort on Fred's and Charles' part with help from other allies. Fred and Charles came to the meeting in Macon.

Miranda Ivey: Miranda has been living at Vencor Hospital in Atlanta for over a year. In a 1987 automobile accident, Miranda sustained a spinal cord injury resulting in her quadriplegia and reliance on a ventilator. Miranda's family supported her for a year after the accident with a few hours of paid assistance from Home Health, but the family was unable to maintain the effort. After being hospitalized at Shepherd Spinal Center for pneumonia, she was placed in a nursing home in South Carolina which was closed after the death of several people who lived there. Miranda was then taken to Vencor. Vencor has been supporting the costs of Miranda's care since her benefits ran out. Miranda wants her own place to live with the 24 hour support she needs. She has a circle of support with five allies who are working to raise the money Miranda will need to get her own place. The majority of Miranda's support will be paid for by the new Independent Care Waiver, but some necessary costs are not covered by the waiver. Miranda and her circle held a gathering at Vencor so that people could meet Miranda and help out with contributions. Miranda attended the meeting in Macon.

Gary Foss: On March 1, 1992, Gary Foss moved into his own apartment with four hours a day of personal assistance services. This move happened after years of struggle by Gary and his citizen advocate, Sheldon Tennenbaum. During a five year period, Gary lived in three different nursing homes in the Savannah area. Savannah Convalescent Center made efforts to relieve Gary's

depression due to confinement and boredom, but Gary wanted his freedom. His freedom has not come easily and it is still not certain to last. Gary has too much income to qualify for SSI and is not eligible for Medicaid unless he is in a nursing home; Gary has cerebral palsy but no mental retardation which leaves him in a gap as far as agency responsibility for assistance goes. Gary needs more assistance than is available outside a nursing home except under the new Independent Care Waiver. Susan Earl, with the Georgia Infirmary and now Gary's case manager under Independent Care attended the meeting in Macon.

Megan Knight: Megan, age seven, lives at Brook Run (the Georgia Retardation Center) in Chamblee. Megan's parents live in Ringgold. Mr. and Mrs. Knight want Megan home with them, but they will need up to 24 hour/day assistance for this to happen. So far, no help is available. Megan was injured in a swimming accident in August, 1987, when she nearly drowned. Megan's brain was damaged leaving her with seizures, a G-tube for eating, and limited ways to let people know what she wants and needs. The Knight's have had Megan in hospitals and facilities from Michigan to Indiana to Virginia. Their insurance ran out, but the family's income was too high to qualify for Medicaid. The family learned about the Katie Beckett waiver, but were unable to get any help from their local Department of Family and Children Services office. Since Megan's accident, Mrs. Knight has been diagnosed with cancer and her husband has sustained a serious back injury requiring surgery. Megan is now in Georgia, but still a long way from Ringgold and the support she and her family need to get and keep her there remains elusive.

Perspective

This study examines Georgia's long term support services from the point of view of the achievements and aspirations of eleven people with severe disabilities and their families and friends. Their situation underlines the need for systematic redesign of the present system, which is currently dominated by public investment in nursing home beds.

Georgia nursing home operators consider four of these people's needs to be impossible for them to meet because they use ventilators to breath.* This leaves them with the apparent choice of living in a hospital at great public expense or living in a facility out of state. The other six people could or do live in one of Georgia's nursing homes or institutions, but would not choose to do so unless they have no alternative.

A combination of personal and family resources, vigorous and skillful advocacy, and imaginative individualized service development now provides seven of these people with support to live in a way that increases their personal autonomy and supports them to participate in community life. This includes three of the four people the system has found impossible to place and plans for the fourth person's move to her own home are underway.

Each of these pioneering individualized support systems is vulnerable because Georgia's long term care system is dominated by policies and patterns of expenditure which assume that nursing homes and institutions are the necessary, desirable, and exclusive response to severely disabled people whose families and friends are unable to provide most of the assistance they need. The eleven people whose experiences inform this study challenge this assumption: *none of them wants to live in a nursing home or institution and none of them needs to live in a nursing home or institution* as long as the system does not deprive them of the specific assistance they need to live as they choose.

In challenging nursing homes and institutions as the exclusive providers of publicly funded, intensive long term care, these eleven people join their voices with those of thousands of other people with disabilities. Such diverse groups as Disabled Persons International, the American Association of Retired Persons, ADAPT, and the Consortium for Citizens with Disabilities (a coalition of 70 national advocacy groups) now advocate for much greater public investment in individualized support.

* One of these people, who now lives in a supported living situation, no longer uses a ventilator.

A Real Choice

There is still debate about the place of nursing homes and institutions in the long term care system. This debate need not be settled before changes can be made for at least eleven people. These people and their families have decided. They are not debating their choice. They are simply trying to live the way they and their families choose. Their requests are not outlandish in concept or lavish in cost. But what the system makes available is simply not what people want and need. What most people can expect from Georgia's current system is opposite to what people, their families, and allies require. If Georgia's system is to support them, it will need to embrace long term, strategic change toward this objective.

Long Term Objective

Georgia's long term care system offers all people, regardless of disability, a **real choice** between individualized support and nursing home, hospital, or institutional care.

None of the people I met wants to live in a nursing home, hospital, or institution. Everyone I met (and parents for minor children) wants to live at home, to be well assisted, to begin or finish an education, to find a job or vocation, and to keep healthy in ways that don't dominate every minute of the day. In addition, some people also want to work to improve accessibility, to support others who have disabilities and to be politically active.

No one I met needs to live in a nursing home, hospital, or institution if the resources necessary for their support are made available in a flexible, individualized manner, wherever the person chooses to live.

Everyone I met will live in a nursing home, hospital, or institution unless there is basic change in the pattern of services and assistance available in Georgia. If choice between nursing home or institution and support to live in one's own or family home is to be real, Georgia must change its current pattern of service delivery away from facility-based services to individualized support.

Individualized support offers people the help they need...

- ...to pay for and arrange necessary personal assistance services
- ...to find, modify, and maintain suitable housing
- ...to choose to benefit from good health care
- ...to choose to benefit from adaptive technologies
- ...to travel from place to place
- ...to plan, advocate, and arrange, necessary supports and to solve problems to maintain and improve them

with this support, people can pursue their own life choices concerning...

- ...occupation
- ...education
- ...personal relationships
- ...involvement in civic life

Individualized support allows costs to be shared among public agencies and with the person receiving support and the person's family and friends.

Because individualized support is specific to the needs, resources, and circumstances of each person, administrative flexibility in managing a diverse and changing system is crucial.

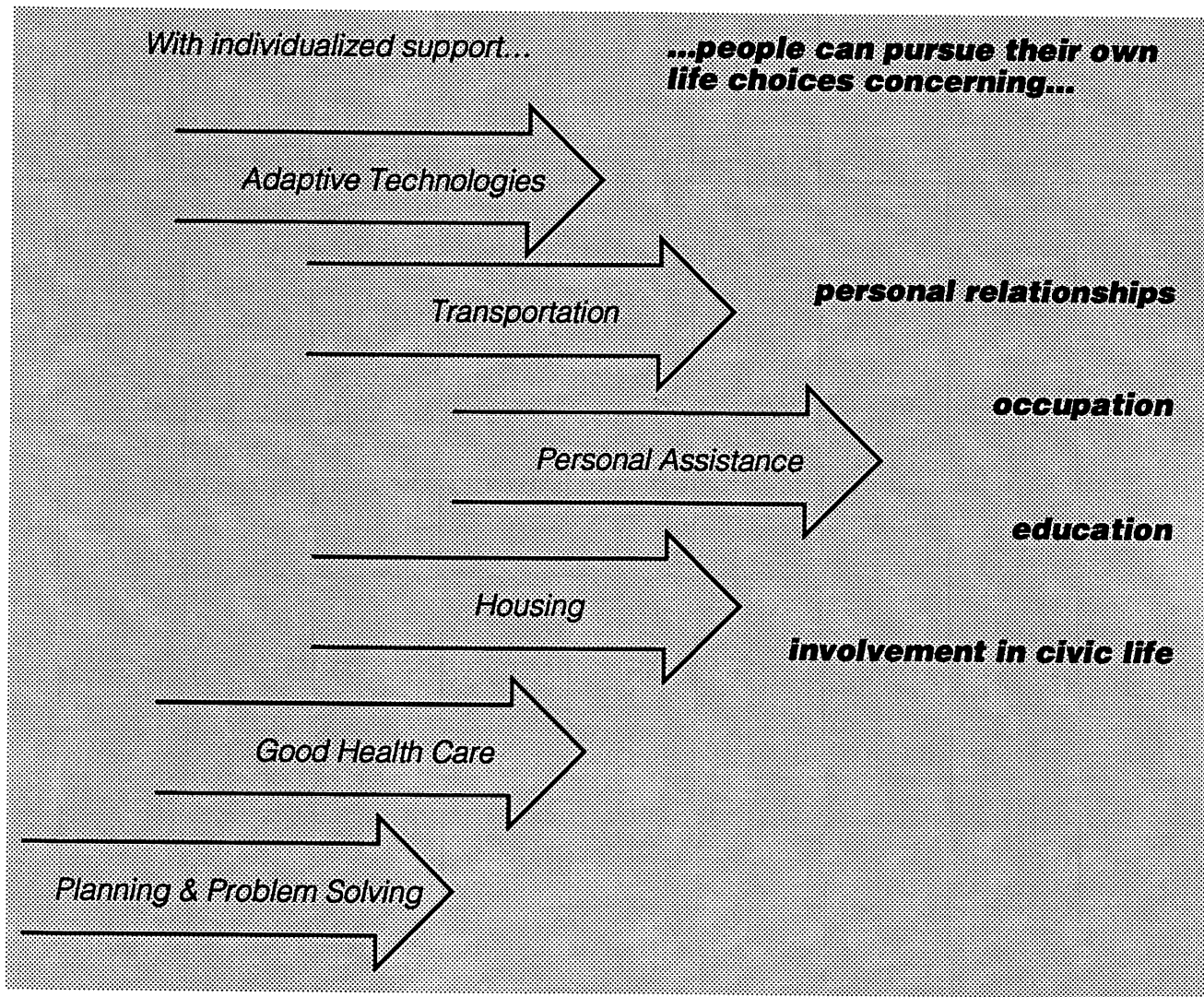
Individualized support offers an alternative to everyone now in a nursing home, regardless of the cause of their disability. People who are severely disabled as a consequence of aging and people with cognitive and emotional disabilities can benefit from individualized support as much as younger people with physical disabilities can.

Individualized support presents the person receiving support with a different mix of risks than nursing home care does. A person who chooses individualized supports trades immediate access to nursing care and a professionally managed lifestyle within a specifically adapted building for greater choice and autonomy in a community environment that may not be entirely accessible, accepting, or supportive.

Personal assistance services (PAS) mean one or more people assisting another person with tasks which that person would do if not disabled. PAS include performing such tasks as...

- Dressing, bathing, eating, using the toilet (including bowel, bladder, and catheter assistance), getting in and out of bed or wheelchair, and ordinary assistance with breathing equipment
- On the job assistance
- Shopping, cooking, and cleaning house.
- Driving and routine vehicle maintenance
- Cognitive assistance with planning the day, maintaining routines, managing money, etc.
- Assistance with communication through interpreting and reading

By supporting the creation of more effective personal assistance services and by supporting people with severe disabilities and their families to work for better policies and more accessible communities, the Governor's Council on Developmental Disabilities can make a vital contribution to the emergence of a real choice for Georgians with severe disabilities.



Jenny Langley: Designer of a Real Choice for System Change

Human service providers have grown accustomed to models developed by professional planners and university researchers. Jenny Langley, her family, and their allies have designed a different kind of model for individualized support. Their method of design matches the concept: it grows from the unique reality of Jenny's choices and the resources available to her from family and friends.

Living in a Jonesboro neighborhood with sister, brother-in-law, and nieces, Sheryl, Joe, Jackie and Jesse. Sitting in the sun. Going to the mall. Helping the kids with homework. Listening to music. Going on a date. Watching a friend play in a band. Having fried mushrooms and a margarita at Bennigan's. Simple, ordinary things. Experiences taken for granted. Not by Jenny Langley. Jenny, 28 years old, is one of many other Georgians whose life changed in an instant when her neck was broken in a car accident. Today, Jenny is enjoying those ordinary moments, but the opportunity to have them has not come easy.

"Technology can keep you alive. You don't have any choice in that matter when you're in an accident. And what do they do when you are released? They say, 'You're alive! We saved you! Now go home.' Go home with nothing."

Many people might think Jenny's biggest battle is with her disability. Learning to live with a body that no longer works. Fearing life without the ability to eat, go to the bathroom, or even breathe without assistance. But

those are not the nightmares that haunt Jenny. Over the past four years her biggest challenge has been the service system that determines where and how people with severe disabilities must live if they require almost any help at all and are unable to afford the costs alone.

Jenny was first injured at age fourteen in a diving accident. This left her paralyzed from the waist down. Neither she nor her family considered her disabled then. Jenny says, "There was nothing to it the first time. I moved out of my family's home. I learned to drive. I helped out by doing secretarial work in my father's business." Sheryl says, "We don't consider that Jenny was really hurt the first time. We always say, 'Since she got hurt...' but that means the second time. Jenny was just fine before this second accident. She was in a chair, but..." Jenny's

nieces refer to when "Aunt Jenny could walk," which has never been true since their births. They actually mean when Jenny could still use her arms, manage a manual chair, live alone, and drive a car.

Jenny's real difficulties began four years ago when she was again severely injured in a car accident resulting in her quadriplegia and dependency on a ventilator for breathing. After a six months' hospitalization at Shepherd, Jenny went home to live with her parents in Yatesville. Sheryl and her two children lived across the street. The family struggled alone to support Jenny. Sheryl helped out when she could, but she was then a single parent working to support herself and two daughters. Mrs. Langley had almost total responsibility. Jenny feels this type and intensity of care is too much for any one person. "When she was doing it, she did it by herself. Sheryl helped, but she had to go to work every day. Mom didn't get to go anywhere. For her to go to the store and buy groceries, daddy had to stay home from work with me. That would drive anybody nuts!" Sheryl concurs, "It would. It gets to where it just gets on your nerves so bad. You can end up literally to God hating each other if you are put in that kind of position. Financially and emotionally, it is more than any family can handle." Sheryl continues, "... but it got harder and harder for us to do all this on our own. Then, of course, the bottom fell out. We got disillusioned. We didn't know what was going to happen. "

The bottom fell out when the insurance company canceled the family's medical coverage. The policy had paid most of the expenses of her initial accident, but the expenses reached the million dollar policy maximum. With Jenny's second injury, the company canceled their medical coverage (the family's automobile insurance was also canceled). The family sought help from the state insurance commissioner who was successful in getting the company to reissue a medical policy, but it was written with a \$100.00 lifetime maximum. This kept the company legal, but was useless to Jenny and her family who had to try to pay for hospital and doctor bills, therapy, and medications from their own resources. The family's total resources were exhausted when a bank foreclosed on the family's home and 30 acres of land in Yatesville. Jenny entered Shepherd Spinal Center with pneumonia, but when she recovered, she had no home to which she could return.

Jenny feels strongly about the power of today's technology combined with a lack of resources to support people once the technology has done it's job. She says, "Technology can keep you alive. You don't have any choice in that matter when you're in an accident. And what do they do when you are released? They say, 'You're alive! We saved you! Now go home.' Go home with nothing."

"Some people believe that a person in my condition should not have nice things and be treated normal..."

With Jenny in the hospital and nowhere else to go, Sheryl and her mother searched for alternatives. They even checked out nursing

homes, but they discovered that no nursing home in Georgia would admit Jenny because of her dependency on a ventilator. The family even considered leaving Georgia and moving to South Carolina or Alabama where a nursing home was at least a possibility. But the family did not want to leave Georgia, and no one, neither Jenny, her family, nor staff and professionals at Shepherd, could stand the thoughts of Jenny in a nursing home.

Jenny's feelings are clear, "Nursing homes are cruddy. There is no way I wanted to live in one." She supports her statement by experiences she had. Jenny describes two situations. At one nursing home, a nurse said to Jenny, "Once you come here, you belong to us." The statement may have been a joke, but Jenny didn't think it was funny. In another facility a nurse told Jenny's mother that she had spoiled Jenny. She said, "She's just a tad spoiled. But we'll straighten her out. We'll take care of that problem." Jenny thinks these statements reflect an attitude many people have about people with disabilities. "Some people believe that a person in my condition should not have nice things and be treated normal. They said they would straighten me out and I'd be better for it."

Sheryl says, "We went and toured nursing homes. We tried to make the most of everything. It was awful and horrible and the worst experience we have all lived through. I do not understand this society's 'let's institutionalize people' theory. We've got more people concerned about laboratory rabbits than we do people. That's sad."

During Jenny's long recovery period, staff at Shepherd grew to care for, even love, Jenny and her family. Nurses expressed their concerns about Jenny's future. They explained their own heart-

break as they work with a person so hard and so close, watch the person regain their health, and then send them off to a nursing home because no options are available in Georgia.

With little hope of finding a better alternative, Jenny began to dream of a future living in a "nursing home with no bugs." "I thought there was nothing else I could do but go to a nursing home. I did not think there were any options. It was all I thought was possible. So the best thing I could imagine was one with no bugs."

When asked to explain how Jenny got from "a nursing home with no bugs" to living at home with Sheryl and her family, she and Sheryl say it happened over a period of time with the help of Shepherd, LADD, Mark Johnson and Pat Puckett.

Jenny's opportunity to live with her family with individualized support happened in the context of a long term collaborative effort by people with disabilities, families, friends and allies. This effort has been aimed at many different problems: lack of accessible public transportation and housing; lack of individualized personal assistance services; medical and other professional control of services; a national agenda that spends billions of dollars a year on nursing homes, but almost nothing in the way of individual and family supports; a non-existent national health care program. There have been some successes, but, in most places, real alternatives to nursing homes remain an illusion.

The first break did not come in a planned and orderly way. In fact, it was forced in a drama unfolding over several months that came to national attention. In 1989, Larry McAfee made national headlines when a federal judge granted his request to have help to kill himself. McAfee, a man with quadriplegia, reliant on a ventilator, living in an Alabama nursing home, thought death was the only alternative to what he considered an unbearable life. Larry, a Georgia citizen, had been placed in an Alabama nursing home when none in Georgia would take him. On first hearing his story, many people believed that what Larry couldn't stand was living with his disability. But it wasn't disability that was intolerable to Larry. What he could no longer take was living in a nursing home, deprived of choice, dignity, personhood, and a future and from which there appeared no escape except death. Larry's real desires emerged when disability rights activists

"I thought there was nothing else I could do but go to a nursing home. I did not think there were any options. It was all I thought was possible. So the best thing I could imagine was one with no bugs."

found a way to meet and talk with him and discovered that his request to die was a desperation move. When someone asked Larry what he really wanted, he said he wanted to go home to Georgia and live in the community with sup-

port, not in a nursing home. Activists joined Larry in a fight for what he really wanted—life in the community with supports, not life in a nursing home or death. A large scale political battle ensued. Disability rights activists from Atlanta occupied the office of the Commissioner of the Department of Medical Assistance as well as the office of the Governor. The Governor finally directed the Commissioner of the Department of Medical Assistance to act on this situation.

Larry's battle was happening about the same time that an amendment to the Georgia Constitution created the Indigent Care Trust Fund¹ which makes money available to hospitals for primary care for people who cannot afford health care. Arrangements were made through the Medical College of Georgia to use a portion of its Indigent Care Trust Funds to start a group home pilot project to include Larry and four other people. In the summer of 1990, Larry moved into the group home in Augusta where he still lives today.

Two of the Georgia activists working on Larry's behalf were Pat Puckett with Creative Pathways and Mark Johnson with Shepherd Spinal Center. Puckett and Johnson decided that Larry's situation had created a new possibility at least for the short term. If Indigent Care Trust Funds could be used to support Larry McAfee, why couldn't they be used to help other people get back to Georgia and out of nursing homes? Mark learned of Jenny who was still living at Shepherd and searching frantically to find an alternative place to live. Mark convinced Shepherd that this might be one way to start an alternative for people when they left Shepherd. In July, 1990, Shepherd initiated a Circle of Support for Jenny with the intention of finding a way for her to live in the community with the support she needed to get on with her life. In November, 1990, the Governor's Council on Developmental Disabilities funded a project on Circles of Support and agreed that Jenny could be included.²

¹ Appendix A describes the Indigent Care Trust Fund.

² Adams, D, et al. (1991) *Circles of Support*. Annual Report to Georgia Council on Developmental Disabilities.

Jenny, Sheryl, and their mother say that in the beginning this "Circle of Support" was a mystery to them. When asked about the circle, Jenny responded, "Circle of support? Well, Pat and Mark introduced me to it, and they were it." Sheryl adds, "Yeah. We met Pat in the hospital, but it doesn't seem like that now. It seems like we've known her forever." Jenny says, "We didn't know who they were. We didn't know what they wanted, or why. We just shut up and they started talking. We were scared to talk to them at first. We really were. Most people who wanted to talk to us wanted money." Puckett reports (1991) that months after she and Johnson came to know Jenny, her mother said, "We could not figure out who you were or why you cared." Jenny is not sure why Pat and Mark singled her out. Sheryl thinks she knows. She says, "I'll tell you why they picked you, Jenny. You were trying so hard, and you'd broke your neck twice, and our parents lost everything, and we were trying as hard as we could, and you'd been hurt since you were fourteen. And there was a lot of support there for you as far as family and friends. It's just that we had all been so brow beaten... And even the nurses didn't want you going to a nursing home."

Several things were going on at about the same time: Jenny's circle got started; Jenny's ideas of what might be possible began to expand; Shepherd began to figure out a way to create something new using Indigent Care Trust Funds; the Governor's Council public forum report, *Speak and Be Heard*,³ clearly demonstrated that many people around the state wanted their voices added to those demanding change; the Georgia Department of Medical Assistance, pushed along by Puckett and others, began to think about applying for a Medicaid waiver that would allow for new and different supports for people with severe disabilities.

Jenny's living with Sheryl was not the first idea out of the circle. Initially, the plan was to develop a group home for Jenny and two other people to be located in Atlanta and modeled after the one established for Larry McAfee in Augusta. Jenny says, "I was going to follow in Larry McAfee's footsteps." But like Larry, asking for death instead of what he really wanted but thought he could not have, Jenny's enthusiasm for the group home was only because it was so much better than living forever at Shepherd or going to a nursing home—in other words, it looked great in comparison to other alternatives she faced. She embraced the

³Adams, D., Johnson, M., & Puckett, P. (1989). *Speak & Be Heard: The Voice of Georgians with Disabilities*. Georgia Council on Developmental Disabilities.

idea with interest and enthusiasm, but it still wasn't what she wanted. What Jenny really wanted, but was afraid to even dream about much less ask for, was to live with her family. She wanted to watch her nieces grow up first hand and continue to be part of the life and activity of her family, friends and community.

Sheryl says that their current living situation came about almost by accident. But it was an accident that would not have happened if Jenny's circle in general, and Pat Puckett in particular, had not been waiting for an opportunity to present itself. The search had been on-going for someone to live with Jenny. They preferred a couple of girls about Jenny's age who could learn to do for Jenny what she needed. Finding the right person was proving difficult. Sheryl says that in a moment of desperation she said, "If somebody would just pay me, I'd stay on and take care of her. I know how." Puckett asked Sheryl, Jenny and her mother if this were a serious consideration. The answer was, "Yes." This was the beginning of Jenny coming home.

Turning Jenny's desires into reality has been a cooperative effort that has brought together agencies, community associations, family, friends and allies. Once the issue of who would support Jenny was settled, Pat found an agency willing to deal with the formalities. She knew Jonathan Kirkpatrick with LADD, an agency in Clayton County, who was willing to work with Jenny in a unique way for Georgia. Jenny and Sheryl located the right house. LADD approached Bob Reynolds a local real estate broker who agreed to purchase the house and rent it to LADD. For the first year, LADD paid the rent from Indigent Care Trust Funds. Jenny and Sheryl now pay their own rent directly. Family and friends arranged to clean, paint and get the house ready. They helped Jenny move in. Sheryl moved into the house on December 1, 1990 and Jenny arrived on December 10.

LADD, Shepherd, and numerous friends including Pat Puckett contributed to setting up the household. A local civic group bought Jenny a television for her bedroom. Members of the Rotary Club bring food to the family on a weekly basis from the Atlanta Farmers Market. The same Rotary has donated \$400.00 toward the purchase of a new van for Jenny. When she moved in, Jenny's room was the den while alterations were being made to the house. Shepherd converted the garage into Jenny's living area. Much of the labor for housing modifications was done at

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cost by a contractor who is a family friend. Home Depot supplied materials at a discount. Jenny’s space was especially designed for her. Shepherd installed a separate heating and air conditioning system necessary to ensure Jenny’s comfort and safety. An alarm system was

added to connect Jenny’s living area and bedroom with Sheryl’s.

In addition to a comfortable home, Jenny requires constant support. She is totally unable to do the things that most people do for themselves. She needs a ventilator to breathe. She has to be suctioned frequently. She can’t be left alone. Four minutes with the ventilator off could add brain damage to Jenny’s life. Six minutes without the ventilator would end it. In cooperation with LADD, she and Sheryl worked out what they feel is a good system that allows Jenny to be in control of her supports. Jonathan Kirkpatrick of LADD sees Jenny as a supervisor. She does all her own advertising, interviewing, hiring, training, directing, and even firing, if necessary, the attendants who support her. Sheryl assists Jenny by filling out required forms, keeping and reviewing time sheets, and processing payroll. They share responsibility for staying within the allowed budget. LADD is the formal employer of the assistants, pays for the support and takes care of legal requirements such as payroll taxes, unemployment and workers compensation. But, Jenny is in control. LADD also carries a general liability policy for the house in addition to professional liability insurance.

Sheryl talks about their home. She says, “The first thing you will notice when you walk through the door of our home is that it looks like everybody else’s. It’s just a house. We’ve got good furniture and bad. We’ve got artwork. Pretty things and yucky things. But we’re not any different. The girls think sincerely that this is their home and this is the way we live. They don’t see Jenny as different. They love her. They get mad at her. They pick on her. They put up with her. They read to her. They irritate her. Just like kids do to everybody. We’re not any different, and I don’t think anyone who comes through will see any difference. The only thing I do try to do different, maybe, is that I stay on the girls’ case, ‘Don’t leave the skates in front of the door! Aunt Jenny has

got to get through it.' I would imagine that this is the only difference that we have in this house. Other than the fact that we have a lot of reporters and people coming through."

Jenny's life now is beginning to come closer to her dream than her nightmare, but the nightmare lurks as a constant threat. For a long time, she was afraid to have a dream beyond a nursing home without bugs. She went through stages of options that might be better than that, but with help, information, and support she now finds herself living a life that makes sense to her. But problems continue. She still faces the threats of no funding for her support, people who believe she is doing the wrong thing by living outside a medical facility, and the challenge that comes with trying to find good, reliable assistants.

Funding from Shepherd's Indigent Care Trust Fund had a time limit—one year, ending December 1, 1991. Initially, Shepherd funded this alternative for Jenny believing the state of Georgia would have an approved Medicaid waiver (Independent Care) to pick up and continue paying for Jenny's supports. Shepherd also wanted to prove that Jenny and other people with her physical needs for support do not need nursing home care, but rather need assistance to get on with their lives in the community. A year has provided the proof. Jenny has lived successfully and well. But, in the interim, Georgia's economy has taken a downturn, resulting in state employee lay-offs, early retirements, and delays in state funds available to match federal funding. There have been moments when Jenny, her family, friends, and LADD feared that she would have to go back to the hospital or to one of those out of state nursing homes while funding for her support was in limbo. The state scrambled for money to bridge the time lapse in funding from Shepherd and the beginning of the new Independent Care Waiver. Money from the Governor's Council on Developmental Disabilities and from the Department of Human Resources, Division of Rehabilitation Services was appropriated for the interim. Jenny has since become the first person to be supported under this new waived program.

But Jenny's "life on the edge" is still just that. Even though the Independent Care Waiver was approved by HCFA allowing payments to family members (except for parents of a minor or spouses) who provide support for a person, DMA is reluctant to set a precedent of paying Sheryl. DMA officials say that it is not

Georgia policy to pay families for what they ought to be doing anyway. The battle goes on.

Many people and institutions are threatened by the idea that a person with Jenny's needs for assistance can live in an ordinary

"I get specialized care here... In a hospital or nursing home, you don't have a person who loves you sitting by your side twenty-four hours a day. In a hospital or nursing home, they have so many people to take care of. Here, Sheryl, or whoever is helping me, only has to take care of me, not ten other people. You can't get more specialized than that."

home, be supported by ordinary people who know how to do what Jenny needs to stay safe, healthy, active and to enjoy life. The idea turns both our nation's and state's current system of care on its head and threatens the very underpinnings of the status quo. Some people say that Jenny cannot be safe outside of a medical facility (even though no nurs-

ing home in Georgia will allow admission to Jenny) and that she risks too much by living with her family and depending on family, friends, and community services for her supports. Even very positive accounts such as the National Public Radio (NPR) show that highlighted Jenny's life, make statements like "Jenny has taken the risk to be at home when she might be safer in a hospital."

Jenny and Sheryl vehemently disagree. About the NPR show which she and Sheryl generally thought was great, Jenny says, "We did not like that statement! The person who did that thought up that idea by herself. We did not say that. I would never say that." Jenny goes on, "I get specialized care here. You don't get that in a hospital. And far from it in a nursing home." She says that the report was not expressing her feelings. Jenny believes that there are people who sincerely believe that she should be in a medical facility. People who would say, "Jenny, be safe." But Jenny's response is, "Oh, sure. In a hospital or nursing home, you don't have a person who loves you sitting by your side twenty-four hours a day. In a hospital or nursing home, they have so many people to take care of. Here, Sheryl, or whoever is helping me, only has to take care of me, not ten other people. You can't get more specialized than that." Sheryl adds, "I'm never farther away than she can holler. Even if I am, there are two kids who are real good and experienced at this who can let me know if Jenny needs something." Jenny says, "Or a bunch of other

people. There're people in and out all the time. My other sister, my mother, Sheryl's husband, my boyfriend. All of them know how to take care of me. Anybody who is with me does. Here you only have to take care of me."

Doctors and other professionals at Shepherd agree that Jenny is safer at home than in the hospital—even a good one. Jenny and Sheryl tell of going to the hospital when Jenny had bronchitis and pneumonia. A doctor examined Jenny and said, "Well, you just look too healthy to put in the hospital. You'll be really sick if you come in here. Your sister can take you home." Another Shepherd professional in the respiratory department told Jenny, "At home you've got friendly germs. Sitting in the sun will make Jenny's lungs clearer."

But both Sheryl and Jenny know that Jenny's life is risky no matter where she is. They have taken careful steps to manage the risks at home and believe they are no more dangerous than being in a facility. People who work with Jenny know what she needs. They are not just generically trained for "the disabled." They don't pretend to be doctors, nurses, or therapists. They are specifically trained to do just what Jenny needs. They also have back-ups for every piece of equipment in case of emergency . They've developed a close relationship with Todd Tyson, a former respiratory therapist, who now owns a business, Hi Tech Home Care. Sheryl and Jenny know they can count on him day or night if they have equipment problems. Todd is one of the people who got involved in Jenny's life as an employee but who has become one of her circle of friends.

Sheryl and Jenny have worried about power failure. To manage this risk, they dealt directly with Georgia Power who put them on the priority list for first in line restoration of power in case of an outage. They've had one occasion to check out Georgia Power's response. Sheryl said when the electricity went off, Georgia Power called immediately, said they knew we were out, and they would have it back on in less than an hour. Georgia Power also has a generator that they could bring out if power could not be restored within an hour. Jenny maintains back-up batteries for her wheelchair and ventilator. Jenny also says, "If something bad happened, we'd just have to take me to the hospital. It's just like any normal person if something horrible happens."

A person would be mistaken to believe that Jenny and her

“...we are teaching the community. I guess the first thing is that we are all happier. Jenny’s happier, we’re happier, and everything. People see us sitting in a meeting, eating lunch, enjoying life. People at the mall see us. People at Bennigan’s see us. The community sees Jenny out and about. She’s taught the girls that life goes on and to be thankful for what you do have. To live every day to its fullest and enjoy it...”

family are only recipients of care. Jenny contributes in all kinds of ways. Jenny says her job is not to be a passive receiver of care. She says it is her responsibility to know what she needs to take care of herself even if she can’t do it without help. “That’s my job. I’m supposed to know how to take care of me. And if I can’t do it, I can ask someone.” Jenny’s life at home and in the community is

full of ways she is an active participant in her own life and that of others. Sheryl and Joe have gotten married since Jenny came home. Jenny’s nieces, Jesse and Jackie, help Jenny by turning the T.V. on and off. Jenny helps them with their spelling. Jenny gets money from state and federal taxes to pay for her support, but her family contributed everything they had trying to support Jenny alone. Jenny works to teach people that life can be good even if you use a wheelchair to get around and a ventilator to breathe. She goes down to the legislature because she believes her presence is a necessary and constant reminder that just because you are disabled doesn’t mean you are pitiful or unhappy. Jenny is a peer advocate, on call to talk with people who have had an accident and need someone who personally understands their situation and can also be a role model for what life can be like even if your body doesn’t work. She is willing, ready, and able to speak to groups who are interested in learning about her own life, the battles she has fought, and the war that still rages over our responsibility to and for each other.

Sheryl has her own thoughts about a major contribution that Jenny makes. She says, “But if nothing else, we are teaching the community. I guess the first thing is that we are all happier. Jenny’s happier, we’re happier, and everything. People see us sitting in a meeting, eating lunch, enjoying life. People at the mall see us. People at Bennigan’s see us. The community sees Jenny out and about. She’s taught the girls that life goes on and to be thankful for what you do have. To live every day to its fullest and enjoy it. She’s even taught Jackie’s classmates. They all talk to her... Jenny’s the best aunt the kids could have because she gives them someone to go and talk to, she helps them with

their homework, she goes with me to school meetings about the kids. They are both better people for having Jenny and me here for them.”

But Jenny and her family can’t continue their contribution without help. The level of support she needs physically, emotionally and financially is more than any one family can provide. Her family, friends and allies have supported Jenny for years. But, even with their help, she can’t financially afford the 24 hour support she requires. We owe Jenny acknowledgment and continuing support for all she and her family have done.

Striving for Dignity and Choice

The people I met during this study don't fit convenient stereotypes of "the disabled": they are not pitiful; they are not sick; and they are not satisfied "consumers" of available services. They have thought carefully about their situation and have practical ideas for bettering their own lives and for changes that would greatly improve the quality of the long term care system. All of them feel and fight the threat of isolation and passivity which is enforced by current long term care policies. Most of them want to work along with other people with disabilities and their allies to make changes that will benefit everyone in Georgia.

This section collects several documents that reflect people's understanding of their own situation and their work for change. It includes...

- ...an account of some of the work of a circle of support formed around Miranda Ivey.
- ...a summary of a personal futures planning meeting held by Fred Pinson and his allies
- ... testimony to a DHR public hearing by Tony Cordova
- ...summaries of interviews with Wayne DeLoach and with Shane Barrow and his mother, Emma Jane Barrow
- ...a letter which details the policy barriers frustrating the long term efforts of Gary Foss and his citizen advocate
- ... a letter from her mother which describes what is necessary for Megan Knight to leave the institution

Each of these accounts reflects the perceptions and beliefs of the people involved. I have discovered nothing in the course of my study that contradicts the facts that they present, but I did not attempt to verify what they said.

Miranda Ivey

Pat Puckett

[Adapted from two articles
written in February, 1992.]

Miranda Ivey sustained a spinal cord injury in a car accident in August of 1987. As a result, she has quadriplegia and relies on a ventilator. For over a year after she was released from Shepherd Spinal Center, Miranda's family tried to provide the necessary support at home. They received some Home Health Services and, out of their own resources, purchased five hours a week of outside help. But it wasn't enough. In June of 1990, Miranda was readmitted to Shepherd with pneumonia. "I told the people at Shepherd that if they sent me back home, I would die. It isn't that my family didn't want to help; they simply couldn't do it."

In August of 1990, Miranda was placed in Ann Marie, a nursing home in North Augusta, South Carolina. Miranda reports that this Home "was OK. I got up every day because I had a portable vent then. We went out of the Home to do things and there were other young people there." In the Spring of 1991, the nursing home began experiencing problems. "They couldn't get a doctor for the Home. Several people died so they decided to close it down."

In April of 1991, Miranda was relocated to Vencor hospital in Atlanta. Vencor accepts Medicare payments but not Medicaid. When Miranda's Medicare days were exhausted, it looked as though she might face yet another out-of-state placement. But Miranda called her local legislator as well as a TV station. For the time being, it appears that Vencor administration will allow her to remain until long term, community-based services can be established.

In December of 1991, Pat Puckett and Valencia Thomas initiated a Circle of Support for Miranda Ivey. The purpose of a Circle of Support is to strengthen people's ability to help and support one another in creating a desirable future. A "Personal Futures Plan" emerges over time as people build trust, work together to clear away obstacles, celebrate successes and most importantly—"hang in there" until the desired future becomes a reality.

Miranda's Circle meets every Thursday afternoon. We mainly visit, laughing, joking and occasionally crying with frustration about why everything takes so long.

We began by dealing with some of Miranda's concerns. "Have I been declared incompetent? How much was the insurance settlement? What happened to the

money? How much is left? Is it too late to file any further law suits?" Pat did the legal research and located the attorney who handled Miranda's case. Valencia wrote the attorney for an accounting of the funds. These issues have been resolved to Miranda's satisfaction.

Next, we began to get others involved. We invited Patricia Roberts, Miranda's dearest and oldest friend to join us whenever she could. We explored the possibility of she and Miranda sharing a home. Although this idea probably won't be workable because of Pat's schedule, she is keeping her eyes and ears open for a house mate.

In December, we introduced Miranda to Patti Neighmond of National Public Radio who did a story on people who need long term support. The night before this story aired Miranda decided to cancel her "Do Not Resuscitate" order "because now I've got a reason to live and something to hope for." Since the NPR story aired, Miranda has been interviewed by the *Atlanta Journal* and by the *Spinal Network*.

Another issue of importance to Miranda was the replacement of her "pacers", phrenic nerve stimulators that allow Miranda to breathe off the ventilator. Valencia wrote to Warm Springs and to Shepherd to explore the possibilities for surgery. Warm Springs does no surgery and Shepherd has virtually ceased using this procedure even with privately insured patients. It is very expensive (\$65,000 or so) and has inconsistent results. Two weeks ago, Miranda decided that she would not pursue this matter any further; "I'd rather concentrate on raising money for other things."

As we got to know Miranda, it became increasingly evident that keeping her spirits up was the most important task. "I feel like I have been sentenced without committing a crime." Miranda hates being in bed all the time and frequently reminds us "I haven't been outside since last April." So in January, we began working with Vencor to get a portable ventilator for Miranda's wheelchair. Pat found someone to loan Miranda a vent and succeeded in securing Vencor's permission for us to use it in the hospital. (This took a month because a new policy had to be written and cleared through corporate channels.) Miranda's power chair is "down"; she is waiting for the parts to come in. As soon as her chair is fixed, we can go to work on the next steps.

In the short range, we are working on getting Miranda out of the hospital for short periods of time. While this may seem like a small step, it will be complicated. Will there be enough staff to dress Miranda and transfer her into the

chair? If Vencor doesn't have the staff, can we locate volunteers? If we can't find volunteers, can we locate resources to pay someone who already has the necessary skills? If we can't find skilled people, can we train them? How long will it take for Miranda to develop the stamina to be up for extended periods of time? ("Up time" is usually a gradual process; most people can't get up and stay up for six hours at a time unless they build up to it.) As Miranda puts it, "I need contact with the outside world." Re-connecting with old friends and meeting new ones is an essential next step especially since her house mate(s) and personal assistants have not yet been identified.

In the long range, we are working to locate the funds necessary to support Miranda in her own place. We are preparing a video tape with the help of a volunteer. We will use this tape to invite Evander Holyfield to join us in fund raising efforts. (Miranda worked at the Boys Club and knew Evander well as a youngster.) Another long range fund source is the Independent Care program, a Medicaid waiver. But even when this program materializes, we will need help with all the "start-up" costs — locating and modifying a house, securing furnishings, etc. Family will help on some of these items but there is still a great deal to be arranged before Miranda realizes her ambition of "getting my life back."

Miranda's circle of support has resolved some of Miranda's concerns about her legal and financial status. Her situation has been made visible to policy makers and to the public. Miranda's decision to cancel the "Do Not Resuscitate" order is a direct result of the circle. Within the next few weeks, she will have the opportunity to leave the hospital for short periods. The circle will continue to work toward finding the right house mate(s) and personal assistants. As we get clearer on these issues, we will get clearer on how much her long term supports will cost. Based on our experience with similar demonstration projects, we anticipate that services will cost about \$200 per day.

WHAT A DAY!

Pat Puckett

"I want ...(whoosh) to cancel ...(whoosh) the DNR order." Those were the words Miranda spoke today. It took a while for her to get the sentence out because of the time it takes for the ventilator to fill her lungs. I listened as she and her doctor casually chatted about her decision to live. You see, DNR means "Do Not Resuscitate". It means "if my heart stops, let me go — no heroic measures." The doc said "no problem, we'll change it but how come you didn't tell Dr. Whosit? What would have happened if your heart had stopped between my last visit and today? The last laugh would have been on you, huh?" Miranda just smiled. After assuring her that she would be resuscitated if necessary, he asked about her interview on National Public Radio. "Of course, you didn't say what I wanted you to say anyway — that you had the best lookin' doctor around!" Again, they exchanged smiles.

My friend, Valencia and I sat there not quite believing our ears. Neither one of us knew that Miranda wanted to die. She's only 36 years old. She doesn't have terminal illness and she's not in severe pain, at least not physically. But until today, she had the worst kind of "condition" — a life devoid of hope. After the doctor left, I asked "woman, you had a DNR order? Why?" "No reason. . . to live. . . 'til now." A simple, straightforward answer to the most complicated and painful question a human being will ever face: When to live and when to die?

At first glance, many people would say that Miranda's choice to die is understandable. How many times have you heard "I'd rather be dead than 'a hopeless cripple' "? When people say this in my presence, they often quickly correct themselves. "Oh, I don't mean you" they'll say. "I don't even think of you as disabled!" Well, I am disabled. So is the metamessage "I'd rather be dead than be you."? It takes time, earnest listening and, most of all, personal experience for non-disabled people to see the real reason that Miranda chose death. It is preferable to her full time occupation — patient — an occupation that's life-defining. It dictates where she lives, what she eats, and who touches her. She's no longer "Miranda, the woman who works at the Boys Club, hangs out with friends and volunteers at the church." The alpha and the omega of her existence is "Miranda, the vent-dependent quad" who stays in

bed all the time, touched and turned by people she doesn't know very well, connected to a ventilator that's plugged in to the wall.

But the promise of a different life changed Miranda's mind. With some help — both paid and voluntary — she will have a regular life. She will find a place to live, choose some folks to help her, leave the hospital, get out of bed every day, ride around in her wheelchair with its portable vent, have fun with friends, volunteer and perhaps work again. On occasion, her status as "patient" will be there, but it will be just one aspect of her life, not all of it. Why does Miranda hope? Because Larry, Jenny and Charles along with their supporters have shown Miranda the possibilities. And she's part of a national network that extends from Massachusetts to California. People with disabilities are fighting for the freedom to choose where they live, with whom and how. It's an honor to be side by side with her. And it was an incalculable gift to witness the re-birth of hope.

Thanks Miranda!

[Miranda still lives in the hospital as of June 1992.]

Planning a Desirable Future for Fred Pinson

[This is a record of a personal futures planning meeting facilitated by David Truran.]

Introduction

A futures planning session can be completed in one day, but it is just a beginning. The process helps to identify desirable images of the future and strategies for getting started in productively working for that future...

This working document looks at background, problems, and choice structures at work in Fred's life and in the lives of the participants. Considering that information, it then projects desirable images of the future that match what Fred wants to happen over the next few years. The plan finally considers strategies that might be useful in making the envisioned future happen. This is a working document in that it helps focus work and desires that have been going on for a long time. It marks a commitment by all the participants to work towards a more desirable future for Fred Pinson and hence for all of us.

This brief report is not meant to clearly describe an ideal futures planning process. It is an abbreviated record of this specific planning session and will serve as an ongoing planning and monitoring document for Fred and the other participants.

Participants

The people listed below met on September 3, 1991, at the home of Charles and Linda Mingle for the purpose of helping plan for a desirable future for Fred Pinson.

Fred Pinson: Fred wants to "find a better living arrangement" that is located "near a job" that will allow him to use newly acquired and developing computer skills. Fred is thirty years old and has lived in a nursing home for about eight years.

Kathleen Pinson: Kathleen is Fred's mother.

Charles and Linda Mingle: Charles and Linda are citizen advocates in relationship with Fred. They are helping him find a better living arrangement and acquire the skills to get a job.

Lee Ann Pendergrass: Lee Ann is the Independent Living coordinator and met Fred, Charles at a recent training on alternatives to guardianship sponsored by the American Bar Association and the Georgia Advocacy Office. Lee Ann hopes to help Fred attain his dream of getting out of the nursing home and becoming productive.

Valencia Thomas: Valencia works with the Atlanta Center for Independent Living. She has known Fred for some time and wants to help.

Tom Tedards: Tom is with the Division of Rehabilitative Services. He is Fred's case worker and is particularly interested in helping Fred become employed (although he may be able to help with other things, such as renovations for accessibility to the place that Fred ends up living).

David Truran: David works with the state office of the Georgia Advocacy Office and was asked by Charles to facilitate this futures plan so that the other participants could sit back and focus on the content without having to manage the actual planning process.

Background

We spent some time trying to get a sense of Fred's past and of the root structure of his interests and desires. Although the information was not collected in chronological order, it is listed that way here to make the flow more coherent to the reader.

Birth (30 years ago): Doctors said that Fred "wouldn't survive the night." He was born premature and had an extremely low birthweight. For whatever reason, this has resulted in Fred's fairly severe cerebral palsy.

Fred remained "part of the family" until "my parents couldn't take care of me" at about age 22. Ms. Pinson described Fred's roll in the family up to this point as being the "schedule keeper" for his younger siblings.

Public School (9th grade, age 16): At this point, Fred was the "first student" mainstreamed into DeKalb County public schools. Neither Fred nor his mother could remember why this occurred. According to Ms. Pinson, "it just happened. Fred and the bus driver cooked it up."

Admission to the nursing home (about age 22 - at the end of public school): When Fred became too heavy for his parents to take care of him, they explored other options and settled on the only one available — placement in a nursing home (at first, totally private pay, but now with the support of SSI and Medicaid). Problems at the nursing home have been (and continue to be) numerous, for example:

- Fred wasn't allowed to eat cookies in his room. Staff were apparently afraid that he would choke and that the nursing home would then be sued. Vigorous advocacy successfully resolved this in Fred's favor.
- The nursing home is always noisy and impersonal.
- Choices are always severely restricted.
- The most basic assistance is often unavailable (for example, if Fred gets sick or needs to go to the bathroom at night, he may not get any assistance at all until morning).
- Fred can only leave the nursing home for a limited number of days per year, or he will lose his "slot."

Fred meets Charles and Linda (about six years ago): About six years ago, Charles and Linda were introduced to Fred through DeKalb County Citizen Advocacy. Over the years, the relationship has blossomed and now the three are involved on many levels. For example, Charles and Linda have both learned caregiving techniques that are important for Fred's everyday life. Fred and Linda enjoy games and activities like Dungeons and Dragons. All three spend a lot of social time together and have attended out-of-town overnight events together. Charles has become Fred's representative payee for certain purposes and both Charles and Linda have advocated on Fred's behalf many times. They are currently allied with him in this futures planning process and are actively hashing over strategies (such as possible architectural renovations and attendant care funding mechanisms) that will result in Fred getting a better place to live in a decent neighborhood (including the possibility of coming to live with Charles and Linda on a permanent basis) with better things to do during the daytime (job training or work).

Fred's relationship with Charles and Linda has resulted in other significant landmarks:

- All three attended a lifesharing workshop last November that marked a new dimension to their relationship.
- Charles introduced a friend, Jeff (a professional computer programmer), who shares with Fred a common interest in computers and who is teaching Fred the "C" language which might open up job possibilities.
- Fred and Charles attended a recent workshop on alternatives to guardianship that has added new allies to their lives.
- In 1985, Fred acquired an AT&T 6300 computer which has allowed him to communicate by telephone. He has also become familiar with Word Perfect, a top-end word-processor.
- Fred has realized that others share his dream of having his own place with the support that he needs to have his physical needs met and to become productive.

Choices, environmental barriers, and problems

A lot of problems became apparent in looking at Fred's background. We summarized the environmental barriers and problems as follows...

- The nursing home schedule in and of itself denies choice...
- Fred has had little or no choice of job training and he has never had a paying job of consequence...
- Fred has not been allowed to choose where he lives...
- He has little control of his schedule outside the nursing home...
- The impersonal nature of the nursing home denies many personal rights (such as the right to privacy as the typical citizen understands it).

The following choice structure is generally at play in Fred's daily life...

By Fred..

- Watching TV. (if he is positioned to see it)...
- Eating cookies or snacks (if he has them & if someone will help)...
- Using his computer (if Fred is up and the computer is working)...
- Using the telephone (if the computer is on and he is in front of it)...
- Choosing food (only if out with mother, Charles, or Linda).

By Others...

- Wake up and bed times set by nursing home...
- Meal times...
- Menu (sometimes can choose ice cream over the standard dessert)...
- Bath times...
- Can't leave nursing home (leaving too often will threaten funding)...
- Has to wait turn for the bathroom (if staff are available)...
- No vacation...
- Must follow the nursing home schedule of outings (even though it is mostly inappropriate for Fred)...
- No say about almost all issues relating to mobility and autonomy...

Preferences/Images of a Desirable Future with Related Strategies

During the day, Fred thought long and hard about the future. We generated these preferences, images, strategies and action steps from his wishes tempered by the contribution of the other participants. Fred, Charles, and Linda will later prioritize the various issues and then begin working the plan. They will involve those who attended the meeting and others to make things happen.

A decent place to live in the community: Fred wants his own place. He prefers an apartment with a roommate who could function as a back-up attendant. Paid attendants would take care of most of his physical needs. Right now Fred needs somewhere between nine and eleven hours per day of attendant care (getting up in the morning and eating breakfast and then getting set for the morning at his computer, help with lunch and then with the bathroom, help getting set for the afternoon, and then help with dinner, evening activities, and then getting ready for bed). The actual pattern of attendant care support depends on Fred's needs and the style of residence that evolves. This assumes the current daytime schedule. Work and work training will change the pattern of help needed on a daily basis. Support from technological devices might eventually reduce the need for daily assistance by several hours. These issues will be addressed throughout the document. Right now, this apartment should be located in a typical neighborhood in DeKalb or Gwinnett county (eventual use of public transportation might make DeKalb more desirable). Right now, Fred doesn't care much about the location of his future home in relation to shopping areas and other typical conveniences. He'd like to be near a mall and fairly close to his family and to Charles and Linda. Many locations in DeKalb and Gwinnett fit this bill.

Strategies/action steps

- Contact Decatur DeKalb Housing Authority and explore the Section 8 rent subsidy certificate (may be used in any location) - 373-4460.
- Consider application to DeKalb and Gwinnett community residential services and ask them to design a personalized option for Fred. DeKalb - Oreta Cook, Developmental Services Chief, and Fanny Bell, Mental Retardation Specialist - 2321-9363. Gwinnett - Pat Millschlagle, Developmental Services Chief- 963-8141.
- Consider United Methodist group homes. Malone Dodson (probably not a possibility because the living situation will not be personalized to Fred's needs and interests).
- Contact Nancy Elliot with Creative Community Services for ideas and possible roommate arrangements or personal support arrangements - 651-2310.
- Check out resources with the state-level developmental services. Possible use of Medicaid Waiver funds or state institution funds. Charles Hopkins, Director of Community Residential Services - 894-6315. Dave Evans, Director of the Mental Health, Mental Retardation, and Substance Abuse Section (might know how to creatively use institution funds) - 894-6300.
- Check out the OBRA folks for the possibility of using the nursing home funding in the community- 894-6366.
- Check out the possible funding sources for home renovation
- Check DRS (Tom has specs. - can pay for widening one external door, one interior bathroom, one interior bedroom, bath bars, and maybe some environmental controls)
- Contact Tom Kohler and find out how Jim Burke got his accessible bathroom - 127 Abercorn Street, Savannah, GA 31401.

- Also, ask state and OBRA about options for remodeling to prevent institutionalization.

Mobility/Attendant Care/Personal-Technological Support

These three issues, although separate in function, are enmeshed in the style of residence and kind of activities that evolve. We considered what Fred needs to build his dream. Fred has got to be able to get to work training and eventually a job. He is getting training from Jeff in the nursing home, but this will probably have to be augmented by some kind of formal education or training to enable Fred to get a good job. Some level of attendant care will be necessary, but this depends somewhat on technological and personal support (which doesn't much exist in Fred's life except for his computer).

- In DeKalb County, public transportation is definitely an option (door to door service is a possibility to and from work for \$2.00/day!). Explore and find out how to use this system.
- Check out ways to pay for attendant care. (Indigent care funds from hospitals, for example, now help 8-10 people per year for up to 30 hours per week for evenings, weekends, and holidays and pays \$7.00/hour. VR can pay for 4 hours per day of attendant care at the work training site @ 6.75/hour.)
- Contact S.M.A.R.T. Exchange for information on the latest technology. Bonnie Webb, Information Coordinator, S.M.A.R.T. Exchange, P.O. Box 724704, Atlanta, GA 30339 - 238-4694.
- Contact Joy Kniskern, Rehabilitation Technology Manager, to check out funding sources and latest technology - 894-6744.
- Contact the Center for Rehabilitation Technology, John Goldthwaite, and determine whether or not a new evaluation might help - 894-490.
- Check options for school to pay for classroom assistance (use ADA if necessary).
- Monitor Georgia's CSLA application (Mark Johnson, Pat Puckett - 292-6501, Dottie Adams) and see if Fred could get help if the application is funded.

Job Training/Employment

Fred has had some training as a computer programmer and operator. He likes using the computer and wants to learn more and eventually become employed in the computer industry. He has mastered Word Perfect and several outdated languages (Basic and COBOL) and is currently learning the "C" language from Jeff, who comes to the nursing home about two hours per week for that purpose. Jeff thinks that Fred could get a job with an understanding employer after he has mastered "C" and written several "fancy programs." He thinks that getting a job would be much easier with some kind of formal computer training. One of the barriers for Fred is that many programs are mouse driven and no one has yet found a way for Fred to use a mouse.

- Get Jeff and Fred to think about what type of specific training would work. For example, should a traditional undergraduate degree be sought, or more specific trade school training in computer?

- Check out the Computer Campus at Georgia Tech (what are the options to using a mouse - a laser driven light, voice operation, etc.?).
- Research finance schemes for education (PELL grants, etc.). VR can be the option of last resort, according to Tom.

Overall Strategy:

Fred, Charles, and Linda are the action team that will decide how to implement this plan. They will call in other stakeholders as necessary (to include meeting participants as well as others who were unable to attend).

[Fred is still in the nursing home as of July 1992.]

“The only reason that I have to live in the nursing home at all is because I cannot get the attendant care that I need paid by medicaid in any other living arrangement. I have cerebral palsy but am not mentally retarded. There are many other people in the same situation that I am in. I know of two other people in this nursing home alone who are only here for the attendant care. Georgia must stop putting its disabled people in nursing homes and start including us in everyday life. The process of including disabled people begins with your department; for only after a disabled person's personal care needs are met can he or she look to the future and see what life has in store...”

(From a letter from Fred Pinson to DMA Commissioner Russ Toal, July 13, 1992)

Anthony Cordova
Statement to Public Hearing
Department of Human Resources
Swainsboro, Georgia

April, 13, 1992

My name is Anthony Cordova. I am a C 4-5 quadriplegic as a result of an automobile accident September, 9, 1979. I was born and raised in Colorado. I moved to Augusta to live with my sister and brother-in-law almost 8 years ago after my mother became diabetic and too ill to care for my personal and daily needs of activity. Since that time, I have involved myself with disability rights and advocacy activities to promote a better quality of life for all persons with disabilities.

In the past twelve years I've experienced many changes in my life. My family members have taken on most of the responsibilities to ensure that my basic needs were met. They did this for 11 long years and through it all, none of it was easy, not for me and not for them. However, I have them to thank for not being institutionalized, and being subjected to the substandard and undignified quality of life in a nursing home. I did serve 5 long months in an institution for persons with disabilities. I used the word *served* because it is like serving time in a jail. You are told when to eat, when to sleep and when to do this or that. You don't have many choices in your living environment and you must ask permission for just about everything. Is that any way for a grown adult to live in this great country of freedom? I think not, especially when you have committed no crime against no one. Still, according to a recent study of the Department of Medical Assistance, there are 733 Georgians under the age of 62 who are in institutional settings (hospitals or nursing homes). This doesn't include the hundreds of severely disabled Georgians in risk of becoming the next victims of the multi-million dollar industry of nursing homes.

The sickest part of this reality is that the mortality rate in nursing homes continues to grow and grow ever-so-great annually. The ironic reality is that the nursing home living arrangement is costing as much

as double or more to tax payers than it would for our people to live independently, in communities of their choice, with the help of a personal assistant for a few hours per week. Georgians with severe disabilities need access to independent living centers where they can learn the skills to take responsibility of their own lives, and become productive citizens to their fullest capacity.

I have been very fortunate in this past year. Since April of 1991, I have received funding for personal assistance. I lived in a group home for person's with severe disabilities from October of 1990 to October of 1991. Since then, I've transitioned out on my own. I now live in a one bedroom handicap accessible apartment in South Augusta. I hire and manage my Personal Assistants. It has been like a breath of fresh air to be able to live independently and learn new things every day. I have a good quality of life with dignity and respect in my community. It hasn't been easy but the sacrifices far out weigh the responsibilities and hard work I've encountered throughout the past 12 years of my disability. I will continue to work toward making independent living services available to all Georgians with disabilities. I believe these services are a basic right and not a privilege.

I believe there is a need for a better understanding and more agreement between the Department of Human Resources and the Department of Medical Assistance to bring about the service and needs of disabled Georgians. Both agencies have made good efforts towards this goal, however, there is much work yet to be done. Together, with consumer involvement, we can meet the needs of those who are desperately seeking their dreams out of a lifetime of nightmares.

Shane Barrow

Shane, who is eighteen years old, was injured in a diving accident in September, 1991. He was treated at Shepherd Spinal Center in Atlanta from October 10- December 20, 1991 where he received P.T., O.T., and recreational therapy. On release from Shepherd, he returned home to Hagan where his mother provides most of the care which Shane needs.

Mrs. Barrow used to assume that if you had a traumatic accident you could receive help from the government. She has discovered that her neighbors assumed that she is getting paid for the support she is giving Shane.

- She dresses and undresses Shane
- She does Shane's bowel program every other night, which takes 1-1 1/2 hours.
- Four times per day Mrs. Barrow does an IC (Intermittent catheterization)

for Shane. The catheterization itself only takes a few minutes, but the time is always lengthened by the clean-up period which takes a minimum of 30 minutes.

- Mrs. Barrow gives Shane his medications four times a day
- She feeds Shane, which usually takes thirty minutes
- She turns and positions Shane to avoid skin breakdown. Shepherd recommends that Shane be turned every four hours during the night, but Mrs. Barrow says that she is physically unable to keep up this schedule, and it is usually more like every six to eight hours. She feels bad about this, and worries about its effect on Shane who has very sensitive skin, but she is now working up to her limit.

Mrs. Barrow, who has worked as a waitress and has also run a convenience store, quit work in order to be home with Shane. The only other option for Shane was a nursing home (at a cost of \$49/day or \$17,855.00 per year). Shane and Mrs. Barrow are currently living on Shane's \$422.00 a month income from SSI (\$5064.00 per year). Neither Shane nor Mrs. Barrow can understand why the government is willing to pay so much for Shane to be in a nursing home and so little to support him to stay home. Mrs. Barrow says that she used to assume that if you had a traumatic accident you could receive help from the government. She has discovered from neighbors that they have been assuming that she has been getting paid for the support she is giving Shane. Both she and her neighbors are mistaken. It has been a harrowing and eye-opening experience to learn how little assistance is available to support a person and their family at home.

I wrote this summary after Martha Gilmer and I visited on 31 March 1992. Shane and Mrs. Barrow reviewed a draft and consented to its publication.

-CLO

Because he gets SSI, Shane is on Medicaid. This covers the cost of occupational therapy he receives. He is also covered by Champus. Champus pays for doctor visits, hospital admittance, some home nursing care, some of the required supplies. Champus sends a check for payment directly to the Barrows which they use to pay Home Care for the services they receive. Medicaid picks up what Champus does not cover. Mrs. Barrow says it would be great if

they were able to keep the checks, but they can't. So far, however, Mrs. Barrow has not been billed for any costs that are not covered either by medicaid or Champus.

Mrs. Barrow learned how to care for Shane's personal care needs by attending the Family Training Program offered by Shepherd Spinal Center. This training consisted of 5-6 days directly related to caring for Shane. Mrs. Barrow thinks this training was invaluable to her and without it, she believes she would never have been able to care for Shane. If she did not feel confident about any of the training she received, she could reschedule any particular part until she felt confident about her ability. Shane is totally comfortable with the way his mother assists him. He would be comfortable with anyone who attended the Shepherd Family Training Program attending to his personal needs.

"It's not much of a life, if you're confined to the house and the only way to go out is to go to the doctor" says Mrs. Barrow. Like other people with physical disabilities and their families, the Barrow's have a tremendous problem with transportation. Non-emergency transportation which was available did not have tie downs for Shane's chair and did not have a raised roof. If Shane used this, his neck was severely strained at the end of the trip by the required bending to fit into the vehicle. Mrs. Barrow sold her car and took her income tax return to buy a van which she describes as "old, and it leaks, and it doesn't want to start, the air conditioning doesn't cool, but when you turn it on, it leaks." She hated to buy such an inferior vehicle, but it was all she could afford, and she had to have some way for herself and Shane to get around. The tie downs aren't safe in the van and the lift doesn't work properly. Her next door neighbor has agreed to work on the van to get it in a safe condition. Mrs. Barrow has tried to get the van outfitted by DRS, but she has been told that in order to qualify for this assistance, it must be directly linked to getting a job. Since Shane is still in high school, they have not been able to justify the refitting in a way that meets DRS requirements.

The family currently receives some limited support paid for by Champus and provided by Home Health Services. An LPN, Linda, and a home health aide, Liz, come together for 1 hour/day each day Monday-Friday to help with personal care. They visit during their 8 am- 5 pm work day. This means that when they help Shane to bed, he must go by 5:00 pm. They check Shane's temperature and blood pressure which is the service that actually authorizes their support even though Mrs. Barrow could do this herself. They assist with Shane's bathing (previously 5 days per week, now to be on Monday, Wednesday, and Friday.) They have brought leg bags which Mrs. Barrow uses when the kind she needs are not available. They have helped with certain supplies when Mrs. Barrow can adequately explain what she needs for Shane. They do some range of motion exercises with Shane's arms although Mrs. Barrow doesn't think they do them as Shepherd demonstrated which means raising Shane's arms above his head. When she asked them about this, they say they do the range of motion exercises to the extent that they are trained and authorized. When Shane left Shepherd, therapists were particularly pleased

that Shane's arms were so loose. He is tightening up and after two months is already showing signs of contractures.

Andy Hendrix, a rehab counselor in Statesboro has been working with Georgia Southern to get some adaptive equipment for Shane. John Wallace from Georgia Southern is donating a P.C. Junior that Shane can learn to operate.

The family has been supported by local people in the community. Neighbors built a ramp and enlarged the door so that Shane could get in and out of the house. A young neighbor assists Mrs. Barrow and Shane in getting out of bed and into his chair in the mornings and into bed in the evenings if they are out past the times that Linda and Liz work. Since Home Health Services does not work on week-ends, Shane does not get out of bed on Saturdays. On Sundays the neighbors help her get Shane in and out of bed. It is also a neighbor who has agreed to work on the van to make it more usable, comfortable and safe for Shane and Mrs. Barrow.

"It's not much of a life, if you're confined to the house and the only way to go out is to go to the doctor"

schooling from a volunteer. The regular in-home program which provided a paid teacher has been cut from the school. Shane misses school and

particularly dreams about getting re-involved in sports. This anticipation was heightened by the adapted recreation and recreational therapy which was available through Shepherd.

Shane and Mrs. Barrow are trying to work with the school so he can return. During the day at school Shane will need assistance with his catheter, assistance with eating, someone to monitor his body temperature, someone to give him his medications and make sure he is correctly positioned in his chair (if he isn't seated properly Shane spasms constantly). The school has not refused, but is acting very slowly with any action. Mrs. Barrow feels that they care more about putting surveillance equipment in the bathrooms than helping Shane return to complete his education.

Shane and his mother identify several important areas of support that would allow them to get on with their lives:

- Mrs. Barrow and Shane love each other very much and both have worked very hard to make life outside an institutional setting possible for Shane. Mrs. Barrow has already given up her work to live in poverty with Shane because there is not enough help available to do otherwise. If she did not give up her job, Shane would be in a nursing home. But the intense support that Shane needs is weighing heavily on Mrs. Barrow. She never gets a good night's sleep because Shane needs to be turned during the night. There are two major things she and Shane need: (1) income; and (2) assistance during the night so that Mrs. Barrow can rest. Mrs. Barrow's preference would be to be paid herself for the personal assistance she provides Shane during the day and then to have someone available during the night to assist him while she

sleeps. She would like to find someone to live in who could be available when needed to help with getting Shane up and down, in and out of his chair. Even if Mrs. Barrow took an outside job for pay, the type of work she is qualified to do usually requires variable working hours, week-end work, and availability to go to work on short notice. If she works outside the home, Shane's support from the service system would have to be more flexible and available than if she is paid to support him with additional help at night.

- The bathroom in the home needs modification.. Shane has not been able to get into the bathroom since his accident. DRS gave the family a shower chair for Shane to use, but the bathroom has a tub, not a shower. They have talked with Jackie at the Independent Living Program in Savannah about modifications. A contractor came out to see what is needed, but he has not yet given the family a cost estimate.
- Shane needs and wants to be back in school. He's ready although he is nervous about being around his school friends for the first time since his accident. He will require substantial assistance to attend school. The school, which has not said no, is dragging its feet about getting the support together that will make it possible for Shane to continue his education.
- The Barrow's van must be outfitted to personally accommodate Shane in both safety and comfort. In addition to a vehicle that is reliable, has a raised roof, has safe tie-downs, and a workable lift, the Barrows need air-conditioning. Shane's body temperature is very hard to keep within the normal range. He is extremely vulnerable to external temperature and can have his body temperature drop or rise suddenly depending on conditions around him. The weather has been mild since the van was purchased so this has not yet caused a big problem, but south Georgia gets hot early and she's worried about safe travel in late spring and summer.
- Mrs. Barrow has no medical insurance. This worries her a lot, but she can't afford to pay for any on the \$422/month income and she is unable to work where insurance might be a benefit.

Thursday, April 23, 1992: Telephone conversation with Mrs. Barrow provided an up-date of what has happened since March 31.

Shane started to school on Tuesday, April 21. Mrs. Barrow says that this has already helped their relationship which was becoming tense because of the stress of always being together. She's not sure how school is going to go but is glad that Shane is there. She is taking Shane to school and then goes back during the day to give him his medications and to deal with his catheter. She thinks the school could and probably should be doing this, but she's decided not to push for that this year. As they see how things go, Shane, Mrs. Barrow, and the school will have a better idea of exactly the kind of support Shane will need to attend school successfully.

Mrs. Barrow's niece, who has helped Shane eat at home and is also a student at Shane's school, is helping him eat lunch. She has a Health

Occupation class during Shane's lunch period and has combined her class with assisting Shane. Shane is not eating in the school cafeteria because there is no ramp to the lunchroom. The route they would have to take to get into the lunchroom would take almost the entire lunch break in travel time. Shane is eating in the office of the Vocational Education building.

Shane has his computer at school, but after three days he has not used it. She says so far he's mainly just sitting there. She plans to ask about why he's not using the computer.

Mrs. Barrow says it would be helpful if there was a simple book without "government double-talk" available to the school to support them with Shane.

Wayne DeLoach

Wayne, who is 25 years old, lives with his sister, Gwen Cleary, her husband, Steve, and two children who are school aged. Wayne was injured in a truck accident on January 21, 1990 resulting in a C-5 injury. He was first taken to Bulloch Memorial Hospital but then transferred almost immediately to Memorial Medical in Savannah where he remained for 91 days. From Savannah he went to Roosevelt Warm Springs for 3 months before returning home. He has been back to Warm Springs twice—once in January 1991 to the Independent Living Program, and again in July 1991 to learn to use his hand splint.

Wayne is passionate about being as independent as possible. He doesn't like to ask for help. Before his accident, he never had to. He still doesn't want to even though there are times when it probably would be better if he did. Wayne wants to do everything he possibly can for himself rather than ask someone else for help.

This passion for independence is in tension with Wayne's needs for support as a result of his injury. He requires a lot of physical assistance. He must have help getting in and out of his chair, turning over in the bed, getting in and out of bed, bathing, shaving and dressing. He can't prepare food or get it out of the refrigerator or cabinets.

But Wayne does everything he can on his own. He stays home alone all day while his sister and brother-in-law are at work and the children are in school. Even though he can't prepare his food, he can eat without assistance if his food and drink are set out. He can turn the TV off and on, and can get in and out of the house without assistance. Wayne takes care of his catheter himself.

Wayne's primary support comes from his family who share their home with him, prepare food, do the lifting, turning, moving that Wayne needs which includes Gwen getting up once every night to turn him. Steve has worked out and built adaptations like the ramps and modified door handles which make it possible for Wayne to get in and out alone. Steve also adapted the telephone so that Wayne can answer and make his own calls. Before Gwen and Steve leave in the morning, they get Wayne up and into his chair. Gwen leaves food and something to drink out for Wayne.

Wayne describes himself as a farmer who also knows a lot about carpentry, welding, car motors, electrical work, pipe fitting, roofing and landscaping. Even though being a farmer may not be possible for him now, he still wants to work. He thinks he could be a dispatcher immediately if he can find someone who will give him a chance. He has listened to his CB so much since his accident that he is totally fluent in all the codes and instructions. He is interested in working either with the Sheriff's department or on the campus at Georgia Southern.

Days alone at home get particularly long for a man who has always been a very active, out-doors person. Wayne does not let his reliance on the wheel-

I wrote this summary after Martha Gilmer and I visited on 31 March 1992. Wayne revised a draft and consented to its publication. I talked with Gwen after Wayne's death to make certain she was still willing to have his story included. She graciously gave her consent.

-CLO

chair keep him indoors when the weather is nice. His home is ramped so that he can get in and out of the sliding glass doors leading to the back yard. He takes every possible opportunity to go outside in the yard or to inspect nearby fields being planted and cultivated by neighboring farmers.

Being alone all day, unable to get in and out of his wheelchair without assistance, has combined with Wayne's love of the outdoors to result in several difficult and dangerous adventures. On more than one occasion as he was exploring, Wayne has fallen from his wheelchair and has had to lay on the ground, one time for hours, before someone arrived home to help him back into his chair. Wayne has taken steps to make this less likely to happen again. He has talked with neighbors across the street about listening for him in case he calls out for help. He now wears a whistle around his neck and has demonstrated it for the neighbors so they will be familiar with the sound and will come to look for Wayne if they hear it.

Wayne says that after he got home from Warm Springs in 1990, life seemed to go downhill for him. While he was still at Warm Springs there were things to do like various therapies. When he came home and spent so much time alone with nothing to do, he says he just sat there thinking. He worries about adding to his sister, Gwen's, load. Wayne says he began feeling hopeless and started looking to the bottle as a way to forget what was happening (or NOT happening) in his life.

In January 1991, Wayne returned to Warm Springs to enter the Independent Living Program. This experience turned into a disaster. He went for what was supposed to be a six weeks program, but he was asked to leave after one week. Wayne says he was told to go home and call back when he got his life straightened out. He later found out from a nurse that his record stated that he was dangerous in the halls because he drove too fast in his wheelchair and that he was non-compliant with his therapy. Wayne thus lost his O.T. and support from DRS. Wayne believes that the situation was badly handled. He entered Warm Springs on a Friday, was not informed of the rules, and was sent away without anyone talking to him directly about his behavior. Wayne does not deny the descriptions of his behavior. He does, however, feel that he should have been confronted face to face with what was considered unacceptable behavior so that he could have had the opportunity to do something about it. He says with as many professionals as there are at Warm Springs, surely one could have spared a few minutes to talk with him directly. Wayne worries that this episode will interfere with his getting additional help from Warm Springs and he fears he has gained a negative reputation which he has no chance to challenge.

Wayne currently receives support from two agencies, DRS and Home Care Services. He has two DRS counselors. Judy Stewart, from Statesboro provides follow-up, checks on Wayne's chair, and makes appointments for return visits to Warm Springs for wheel-chair work. If Wayne is in Warm Springs, Gwen Johnson, then takes over as his counselor. She provides follow up while he is at Warm Springs and is responsible for Wayne's Rehab and his application and

admission to the school (VRU). Home Care Services provides two sources of support in addition to the work that Martha Gilmer does with Wayne. He has a nurse, Celeste, who comes once every two weeks. Celeste's visits usually last about an hour while she checks Wayne's blood pressure and heart, checks his feet and toes, cuts his finger and toe nails when necessary, checks for any body breakdown that might lead to a sore, and asks him about how his chair is working. A home health aide, Catherine, who comes for about an hour each Monday, Wednesday, and Friday, bathes and shaves Wayne and washes his hair. She also assists Wayne in working out with arm weights.

Even though Wayne has experienced periods of despondency, he has not given up. He clearly identifies some very specific supports and aids that would help him once again be and feel productive as well as make a contribution.

The following would improve Wayne and his family's situation:

- The bathroom is inaccessible. The family would prefer to build a new bathroom specifically for Wayne off his bedroom. They have been told by Judy Stewart from DRS that they can get help to modify the existing bathroom, but that no help can be given to build a new one. Wayne's brother in law, who is a carpenter, believes that trying to make the current bathroom accessible presents two problems. First, he thinks it would interfere structurally with their modular home because the heating/air conditioning unit is just outside the bathroom. Second, Steve thinks that making their only bathroom accessible for Wayne might reduce the price they could get for the home at re-sale. Gwen and Steve would like to build a new house some time in the future which would mean selling their modular home. If they added an accessible bathroom off Wayne's bedroom, the house would still have one regular bathroom and if the special bathroom was undesirable to a potential buyer, it could be removed without causing a structural problem.
- Wayne could be more independent in the house if light switches were lowered and electrical outlets were higher. Also having the sink, cabinets and handles in the kitchen lowered would help. The family's potential plans for a new home make it difficult to get started on making such changes which also might negatively affect resale value.
- Wayne has no transportation that will accommodate him and his wheelchair. He is able to sit in a car and be buckled in with the seat belt, but when he travels this way, he does not have his power chair once he arrives at his destination. Wayne has come up with an idea for a trailer that his brother in law could build that could be hitched to the back of the family car so that Wayne could transport his chair. Wayne has become interested in trying to get a driver's license again so that he can drive himself. He would like to have a van modified to meet his personal requirements. He has been told by Judy Stewart that if he purchases a van, DRS will modify it and add a lift. Without a job, the likelihood of Wayne being able to afford a van is very remote.
- Wayne wants to try Warm Springs again. There are four things he needs

from Warm Springs: (1) his wheelchair needs to be overhauled and customized (the chair now malfunctions: one arm falls off which has resulted in his falling out of the chair, and sometimes when he lays the chair back it gets stuck in that position and he is unable to change it until someone comes home to assist); (2) he wants to resume therapy for his hand; (3) the splint that was fitted on his last trip broke. It needs to be modified and fixed; and (4) Wayne is now interested in learning to write using the hand splint.

- Wayne would like to enroll in the VRU at Warm Springs and take a course in business or accounting. He thinks that starting at the VRU would make it more likely that he could attend Georgia Southern College to get a degree in business or accounting. This possibility is limited by the transportation problem. He recently had to pay \$150.00 for someone to take him to Warm Springs.
- Wayne wants a job. He thinks he can work now as a dispatcher. He has listened to his CB so much since his accident that he is totally fluent in all the codes and instructions. He is interested in having a job either with the Sheriff's department or on the campus at Georgia Southern (Georgia Southern has the advantage of being where his sister works and might possibly reduce some of the problems associated with transportation, especially if his trailer idea becomes reality.
- Wayne believes that people who are said to be qualified, professional social workers and psychologists should know what they are doing. But some of his interactions with professionals (primarily through DRS and staff at Warm Springs) have resulted in two problems: (1) People call up, talk, offer advice or assistance, but often never call back even when they say they will. People should at least have the courtesy to call back if only to say, "Sorry, we haven't been able to work that out yet." (2) He also feels that the Warm Springs incident which resulted in his being sent home early was not handled professionally or well.

Wayne is ready to move on with his life. He has had the support of his family to the extent they are able to provide it. Wayne wants to be as independent as possible. Wayne has stopped drinking. April 22 will mark the 32nd day since his last drink. He's ready to go, and he knows that drinking was just a way to deaden his senses when there was nothing else to do.

[Wayne died on Friday, June 19, 1992. His death was the result of exposure (heat stroke) when his battery failed while he was outdoors in the sun at a pond not far from his home. Since meeting Wayne on March 31, I had talked to him many times by phone. His life seemed to be heading in a direction that pleased him. He started attending AA meetings and was due to receive his 90 day sobriety pin at AA the evening he died. He was even thinking of the possibility of finding an accessible apartment in town by contacting some of the people with whom he used to work. He did not want to be a burden to Gwen. Wayne had gotten reinvolved with his mother and two aunts. The three of them were planning to accompany him to the Macon meeting on Monday, June 22. He had made new friends. He was thinking about other vocational pursuits (including going to law school).

I talked to him by phone on Tuesday, June 16, and he was really excited about the meeting in Macon. He

was happy to be making a contribution to possible changes in supports for people with disabilities in Georgia. He was pleased that his mother and aunts had decided not only to drive him to Macon but were also eager to participate in the meeting. He was excited about the opportunity to show off the new trailer he had designed for his wheelchair and had someone build for him. The trip to Macon would have been the first test of his new invention.

Gwen Cleary, Wayne's sister, called and left a message on my answering machine on Sunday, June 21. She asked me to return the call. When I reached her, she told me that Wayne was dead and that his funeral was to be on Monday morning at 11:00 am. She wanted me and other people at the meeting the next day to know that Wayne had wanted to be there. She didn't want us to think that he had just not shown up.

Wayne had an unexpected impact on me. I only met him once. We talked and shared hopes and troubles over the phone. I know I will never forget him. My memories are of a man who made an impact on people with the strength of his will and his spirit, his love of independence, and his wish to help himself as well as other people.

I miss you Wayne.]

Gary Foss

[Letter written by Pat Puckett]

November 1, 1991

Russ Toal, Commissioner
Department of Medical Assistance

Jim Ledbetter, Commissioner
Department of Human Resources

Dear Russ and Jim:

Thank you for your interest in Gary Foss. As you know, Gary and his friend, Sheldon Tennenbaum, requested my assistance with the development of a personal support plan. Because of insufficient community-based services, Gary was placed—against his will—in a nursing home five years ago. He now lives in Savannah Convalescent Center; prior to that he was in Cohen's retreat; prior to that he was in Chatham Nursing Home. During these past five years, Gary has experienced severe depression and has, on occasion, expressed suicidal thoughts to his friend, Sheldon. To Savannah Convalescent's credit, they have attempted to alleviate the source of Gary's depression—confinement and boredom. Gary gets out each day; he goes to Georgia Infirmary, to church and out with friends. But Savannah Convalescent is still a nursing home. His property "goes missing"; he has toilet accidents because staff response time is too slow; he has a difficult time dealing with the rules that exist in all congregate living situations. For all these reasons, Gary wants and needs his freedom.

I have enclosed a picture of the future that the planning team created with Gary on October 26. The people involved were Gary, Sheldon, Arnold Young (Gary's attorney and friend) Susan Earl and David Wilson (Georgia Infirmary), Tom Hodgson (Tidelands Mental Health Center), Charles Hopkins (Division of MH/MR), Tom Kohler (Citizen Advocacy-Savannah). It looks as though Gary's individual support plan will require about \$900 per month OVER his income. Russ, I am aware that you suggested (to Mr. Tennenbaum) the Community Care Services Program (CCSP) as a possible mechanism to achieve Gary's goal of supported living. So far, I don't see how CCSP can offer what is needed. The "up side" is that Gary's situation may fuel policy reform. The disability community is especially concerned about:

- 1) Nursing Home Reform (OBRA). Gary Foss is precisely the sort of person for whom this federal legislation was intended. Many states took a proactive approach to the historical practice of "dumping" people with Developmental Disabilities (DD) in nursing homes. Illinois, for example, developed community living alternatives (an OBRA waiver) even though, like Georgia, their Medicaid rates for nursing homes are among the lowest in the nation. Our state's approach was minimalist—do only what the letter of the law requires. Georgia spent virtually no money on the development of alternative living situations but millions of dollars were spent on the "assessment process". The return for that investment was a non-choice, people with

disabilities were told by the OBRA teams— “you either stay in the nursing home or live on the streets”. What a deal! About a year and a half ago, Gary and Sheldon faced this dilemma. Naturally, Sheldon fought for Gary’s right NOT to be homeless. What else could he do? Do public dollars now flow into nursing homes for “specialized services ‘ to people with DD? How much? Why did Georgia opt for this approach in lieu of simply getting people with DD out?

- 2) Institutionally Biased Policy. People like Gary who have an income above the SSI level, are not presently eligible for Medicaid UNLESS they are in a nursing home. Department of Medical Assistance can opt to eliminate this institutional bias. I do not understand DMA’s reluctance to employ the Institutional Deeming Rule which would allow a person’s income to be three times the SSI amount. DMA’s present policy prohibits non-SSI eligible people with mental retardation from participation in the community based MR waiver. The result is that people cannot leave institutions. If, by some miracle, Georgia were to get serious about getting people with DD out of nursing homes, will the failure to use the deeming rule be an obstacle for them, too?
- 3) Dichotomous Policy. It is absolutely unclear to me who is supposed to be addressing the needs of people with developmental disabilities other than mental retardation. While OBRA covers people with MR and related conditions (cerebral palsy is a related condition), people cannot be served by the MR system unless their IQ is 69 or below. How many people with severe CP are in nursing homes because our state has elected not to create a Division of Developmental Disabilities? How many people have a label of retardation only because there was no way to get services without that label? There are some people within DHR who say that the Division of Rehabilitation Services is serving these people. If that is the case, how did they end up in nursing homes? The reality is that for the vast majority of people with DD, no one is providing the needed supports. Unless we have some dramatic changes in policy, people with developmental disabilities will continue to be suspended in “no person’s land” (formerly known as “no man’s land”).

So — what is to be done about Gary? The first complicated hoop is accessing the service delivery system that will get us as close as possible to what is needed. At the moment, Community Care may be the only option because

- 1) the MR system cannot serve him without a diagnosis of retardation. Is there a way to avoid that label? (Gary hates being called “illiterate” or “incompetent”. Is it possible to waive the MR diagnosis? How long will that take? If this barrier can be overcome, then someone has to find the money. MR Medicaid Waiver dollars cannot be easily used because the residential service per diem is \$125.00 per day; Gary needs only \$53.00 per day total. It might be possible to free up state dollars through the conversion process. That is, Tideland’s converts a state-funded residential slot into a Medicaid Waiver slot and uses the freed-up state dollars to fund Gary’s support.
- 2) it is doubtful that the Rehab. system has funds, but this matter will be explored with Gary’s Independent Living Counselor, Jackie Immel. Even if Gary were to

access the Rehab. system, their services are traditionally considered short term. Ultimately, Gary would have to become gainfully employed and self-sufficient. Although he is interested in working and could earn some money, the planning team does not see Gary earning enough to cover the cost of attendant care and living expenses. This is another example of one of those double-bind, all-or-nothing policies.

- 3) the Mental Health system isn't an option because Gary is not mentally ill (But if he stays in the nursing home long enough. . .)
- 4) the Independent Care program would work IF it existed. Given that (a) it can't start until spring of '92, (b) 40% of the start-up dollars were cut in the special session (c) revenue projections are worse than predicted and (d) no one in the General Assembly is talking about tax reform, do you think Gary should get his hopes up? In addition, three people have already been relocated from intensive care units of hospitals. These hospitals invested a year of funding with the understanding that Independent Care would be there for the long haul. Isn't the Independent Care program already at capacity at least for this year)? If you were Gary, would you count on Independent Care?

So—given that Community Care seems to be the best possibility can it be made to work for Gary? To get into the Community Care system, people with incomes above SSI must be handled by three different state agencies: The Health Department's assessment team does the initial assessment and plan of care. The Department of Family and Children Services determines Medicaid eligibility as well as how much Gary will have to pay for his services. (It can take 90 days for the consumer to find out IF they are Medicaid eligible and what the cost share will be.) The Area Agency on Aging assigns a case manager who brokers the services. One has to go through all this in order to get a maximum of \$700 per month worth of services which means that Gary is around \$900 dollars per month short. Can the Community Care ceiling be waived? Why or why not? For how long? Who decides? How does this \$700 per month ceiling compare with the state and federal funds now being spent on Gary's nursing home bed?

At the policy level, it seems that Gary's future is littered with obstacles. But at the implementation level, it is ripe with opportunities. Gary's friends are a terrific source of support. Sheldon manages his funds and is committed to "seeing this thing through"; Jeff and Kathy bought a used lift-equipped van so they can include Gary in outings and in activities; Lynn and Sonny value Gary's participation in the church; Arnold stands ready in case Gary needs legal help; Arnold's wife, Ruthie is there for Gary, too. The local human service system—Georgia Infirmity, Rehab.'s Independent Living coordinator, Tidelands Mental Health Center—are cooperating to make Gary's dream real. This stellar example of local collaboration must not be wasted nor should the opportunity to (re)design policies that work for, rather than against, people with disabilities.

Gary and Sheldon await your advice about what to do next.

[Gary moved out in Spring, 1992 but he still has insufficient personal assistance to live safely.]

Megan Knight

[Letter written by Marsha Knight, Megan's mother]

February 9, 1991

Mr. Russ Toal
Department of Medical Assistance

Re: Medicaid Services for the Handicapped

Dear Mr. Toal:

I am a very concerned parent of a six year old little girl who has just recently gone to GRC in Atlanta. I am writing this letter as I am not sure that I will be making the meeting at the Shepherd Spinal Clinic which is scheduled February 27, 1991, regarding services for Supported Living.

My child, Megan, was injured in our back yard swimming pool in August, 1987 and nearly drowned. It has left her severely brain damaged. We were not only devastated by the loss of our perfectly normal little girl, but also the lack of support from services that are currently available. Since we live almost in Chattanooga, TN, we cannot get any of the benefits of Tennessee. We are almost two hours from Atlanta and it is very hard for us to get any help out of there. Megan has been in Virginia, Michigan, Tennessee and Indiana, where she has gotten some help from rehabilitation hospitals. This, along with home health nursing ate up the private insurance her father had on her. He was also retired from the Navy on a disability and has Champus insurance on her for the rest of her life. I do not know if you are familiar with it, but it is like pulling a tooth to get them to pay for anything at all. They have refused home health nursing, and have told me several times to let my local community help out.

Because of Megan's accident, she has a G-tube for feeding, she has seizures, is unable to perform any kind of response except for when she is happy she smiles and when she is in pain or is unhappy she can cry. We feel Megan is trapped in a body that will not work.

The school system in Ringgold, Georgia, where we live has set up a program for children like Megan. We would like for her to return home and become a part of it, as well as a part of our family. We really do love our child and want the very best for her as all parents do. We also have a four year old little boy who has been involved with her care also and enjoys being around her. We very much would like to bring Megan home but . .

The problem is like this. Her father and I were divorced in December, 1988. He could not handle the pressures at home of taking care of Megan. After her accident, we were sent home with a different child, without any nursing care or supportive services. We had the 24 hour responsibility of taking care of a very sick 3 year old as well as an 18-month old baby boy. Since she cannot do anything by herself and I had absolutely no instruction or help, our marriage crumbled very fast. It was then, that

I began to seek help from everywhere possible. I was given SSI and Medicaid on Megan. This was because our resources were so low that we qualified. Megan was sent to a rehabilitation hospital in Virginia and then returned home after five months with nursing. The nursing care made all of the difference in the world. However, she did get sick at home and we had to send her to another rehabilitation hospital in Michigan. It was our private insurance that paid for all of this. She stayed in Visitors Hospital for 9 months in Michigan. In the mean time, her father got some help and wanted to come home and he could not take the pressure of day in and day out of her care and no one could. You become a prisoner in your own house. Our insurance company in July wanted Megan out of the rehabilitation hospital as it was costing them approximately \$30,000/ a month to keep her there. When we tried to get our nursing at home, they refused. Since her father and I remarried, we were not able to get SSI or medicaid on her. We could not and still cannot afford all of the medications, diapers, and formulas that she needs to take care of her as well as the apnea monitors, etc.

We then had no choice but to place her in the only place that would accept her which was Camelot Care Center in Logansport, Indiana. They took her and because she was not living in our home, we could qualify for medicaid in Indiana. We had heard of the Katie Beckett Program, but in our area it has been the problem of finding out how to go about it. No one at our DFACS office knows or even our DMA in our area does not know. In the meantime, we wanted Megan closer to home and not in Indiana. We tried desperately to get her to our house, and also to GRC in Atlanta. But to no avail did that happen. This was August, 1990. In August, I was diagnosed with cancer and in September, 1990, my husband injured his back at work. So, the chances of Megan coming home for us to care for her was almost decided instantly if we could not get any help in taking care of her. My husband is still currently having a lot of back problems and is looking at possible surgery as well as losing his job.

In December, 1990, we were told that GRC had an opening and would take her. This was the last place we wanted to put her, however, we did want her closer to home as we were not able to visit her at all while she was in Indiana. This was our first Christmas away from our little girl and it was very hard.

We scraped together enough money to get her to GRC on January 31, 1991. she has only been there a little over a week. So far, I am not too pleased with the place. I am totally ashamed of living in the state of Georgia. I can see that most of the money taking care of the children and adults in this facility is administration. I was told by GRC that it costs between \$70,000.00 and \$80,000.00 to care for one individual at this facility. I honestly and truly doubt that the money is being appropriated properly. The equipment that they use is very old. My daughter who has respiratory problems is in a bed that does not even raise up. She will never have a wheelchair designed for her. It will be one that will be made or one they have on hand that can fit her. Her clothes, I am told get lost or stolen and for me to buy second hand clothes for her. I do not want my child looking like a "rag muffin". I do not like to hear all of the negative things they can do for my child and I realize this problem is between me and GRC. I will voice my opinion to them as I already have.

My question is this of you. We are going to apply for the Katie Beckett Waiver, but it is not going to help us out unless we can get some nursing services for Megan. Six to ten hours a month is not going to help us out one bit. We will need at least 12 to 18 hours of nursing a day and probably when she is very sick 24 hours of nursing a day. I am going to have to go to work so we can exist in our household and I will not be able to take care of her 24 hours a day and keep a job, run a household, take care of a 4 year old and it is obvious, her father won't be able to because of his back. I would have to be some superhuman to do all of this. However, I feel that the state of Georgia, and we are definitely citizens. Her father has lived in Georgia all of his life and we have lived here in this house for the past 11 years. We pay taxes also. I feel that our child and the state would be better off if she was taken care of at home. She could have a nurse with her 24 hours a day cheaper than what it costs the state to keep her up. Also, we would be closer to her, she could be around friends and family that love her and we would know she is being taken care of. You could probably save the state about \$40,000.00/ a year by doing this. We have a hospital bed at home and some suction equipment from before. The equipment we have at home is more modern than what GRC has in its facility.

I am not only writing this for our daughter, but for each and every family that has to face this situation. I do hope that you will understand, that you either have to have a lawsuit to take care of someone or be filthy rich, because the average American family cannot handle this by themselves. I do not know if you are a parent or not, but as a parent, you will almost do anything when it comes to your child. I hope you can understand why I am writing this. I want to help change some things that are so remote like institutionalization. This has been the last resort for our child. We would like to get her home as this is where we want her. Because of these laws in the state of Georgia we are unable to have her at home. We very much want her home.

I hope you will take this into consideration, as 3 1/2 years ago, I would not even understand what this was all about. I just assumed, like the average citizen, that if you have a catastrophic illness or tragedy, it would be automatically taken care of by the government—wrong. It is a rough world out there and these people are second and third class citizens in an institution. Just because they are different, does not mean they are not human.

Mr. Toal, this is 1991 and I do hope that we can look for some changes in the future. I hope that you will take into consideration my letter when you address these issues.

Thanking you in advance for your cooperation and I also want to thank you in advance for going to a meeting about Supported Living. I know money is a big factor anymore in budgets, and we are all looking for ways to cut spending, and I honestly believe, if monitored, this can work for the benefit of all.

If you have any questions, please feel free to contact me.

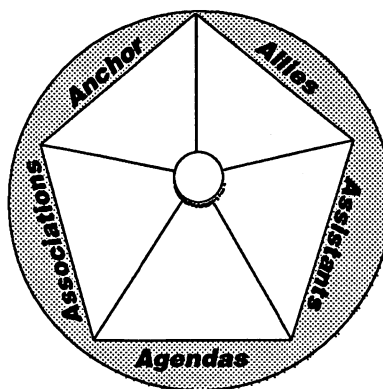
[Megan is still in the institution as of June 1992]

Commitments That Promote the Well Being of People with Severe Disabilities¹

People with disabilities have gifts and strengths, just as any person does. But people with disabilities are often trapped by the assumption that their ability to live as they choose depends on how close they come to being able to do everything for themselves, without help. Under this assumption, the more help a person needs, the more autonomy the person should reasonably expect to surrender. Long term care policies designed on this assumption set up a continuum of care in which receiving more assistance requires a person to accept more restriction. The nurse's "joke" to Jenny – "Once you come here, you belong to us." – captures this reality.

Reflection shows that the assumption that independence requires solo performance is false. What is essential to independence is directing one's own life, in relationship with others one chooses, toward goals of one's choosing. It is possible to do this without being able to dress oneself. Those who are most successful are those most likely to receive or command assistance of many types from many people. Experience shows that people with severe disabilities can live with dignity and autonomy, as Jenny does, when other people receive their gifts, invest in them, and assist them.

As I met Jenny and other people and began to understand a little bit about their lives, I found that this way of graphically displaying people's relationships helped me to understand what is happening now; what is getting in people's way; and what might make a positive difference to the quality of their lives.



¹ Material in this section is taken, with permission, from Connie Lyle O'Brien & John O'Brien (1992). *Essential Commitments: Requirements for Constructive Change in the lives of People with Severe Disabilities*. © 1992, Responsive Systems Associates, Inc.

The diagram, which is expanded on the following page, identi-

Commitments That Promote the Well-Being of People with Severe Disabilities

Anchor

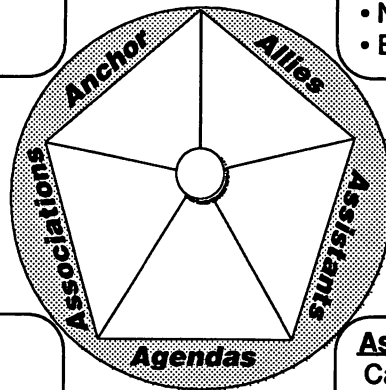
Personal commitment to...

- Be a source of continuity by sharing life over time
- Stand with the person in difficult times
- Grow in knowledge of the person
- Work to create opportunities for the person
- Include the person in life decisions
- Protect the other person

Allies

Personal relationships in which people...

- Share time & activities
- Share knowledge of person's gifts & challenges
- Share knowledge of community
- Help describe a future worthy of investment
- Make contacts for one another
- Lend practical help
- Negotiate conflicts
- Enjoy one another



Associations

Formal & informal groups organized...

- To animate civic life by promoting member's interests
- To develop member's skills
- To work for change in policies & practices members see as unjust or disadvantageous

Assistance

Cash transfer & organized services which make available...

- Money with option of personal control
- Personal assistants
- Links to jobs & learning opportunities
- Devices, adaptations, redesign of activities
- Teaching
- Advice
- Representation

Agendas

Political action to insure just & effective public policies, e.g....

- Personal assistance services
- Inclusive school classrooms
- Necessary assistance for individual employment
- Individual or cooperative home ownership
- Safe & accessible transportation
- Adequate income without stigma

fies five different types of commitments that promote well being in the lives of people with disabilities.

- anchor people, who love you and are a source of continuity and strength over time
- allies, who develop personal relationships with you, help you work toward a desirable future, and share knowledge, contacts, time, activities, conflicts and fun with you along the way
- assistance, either voluntary or in the form of money and service supports (such as personal assistance, adaptive technology, learning opportunities, advice, and representation)
- associations, formal and informal community groups that organized around members' common interests
- agendas, political action to insure just and effective public policies

When ideas and actions toward a desirable future attract these five commitments a person can move into their future with more assurance and personal power, deal better with setbacks and failures, and be and feel more safe and secure.

Consider the general effects of these commitments for people with disabilities:

- Commitments along all five dimensions empower people, the families, and their communities.
- When a whole dimension of commitment is unavailable to a person, that person is more likely to be physically and emotionally vulnerable.
- A person without anchors and allies is unlikely to feel or act empowered, no matter how much assistance is available.
- People's anchors and allies will be stronger and able to accomplish more if they have many connections to community people and groups rather than being totally dependent on the service system.
- When family members (usually mothers, sisters, or sisters-in-law) are completely or almost completely responsible for assistance, the person needing assistance may come to feel like a burden and choose an undesirable living situation to spare family caretakers.
- A service system whose agenda is aligned with a person's

agenda improves the chances that unpaid people will continue to play a part in assisting and supporting the person rather than becoming tired, frustrated and no longer able to provide day to day care and support.

- If assistance is missing or only provided on terms incompatible with the person's sense of a desirable future, it takes much more energy for the person to move toward the vision.
- Assistance is most effective when it fits the person's actual requirements as closely as possible. The best way to insure this is to give the person as much direct control of assistance as possible. This means policies that offer a choice of direct control of money to pay for assistance and a choice about the mix of paid and non-paid assistance the person prefers.
- When people lack good assistance, they may be seen as more disabled or less motivated than they are capable of being and their families may be labeled "dysfunctional," "uncaring," or "overprotective."

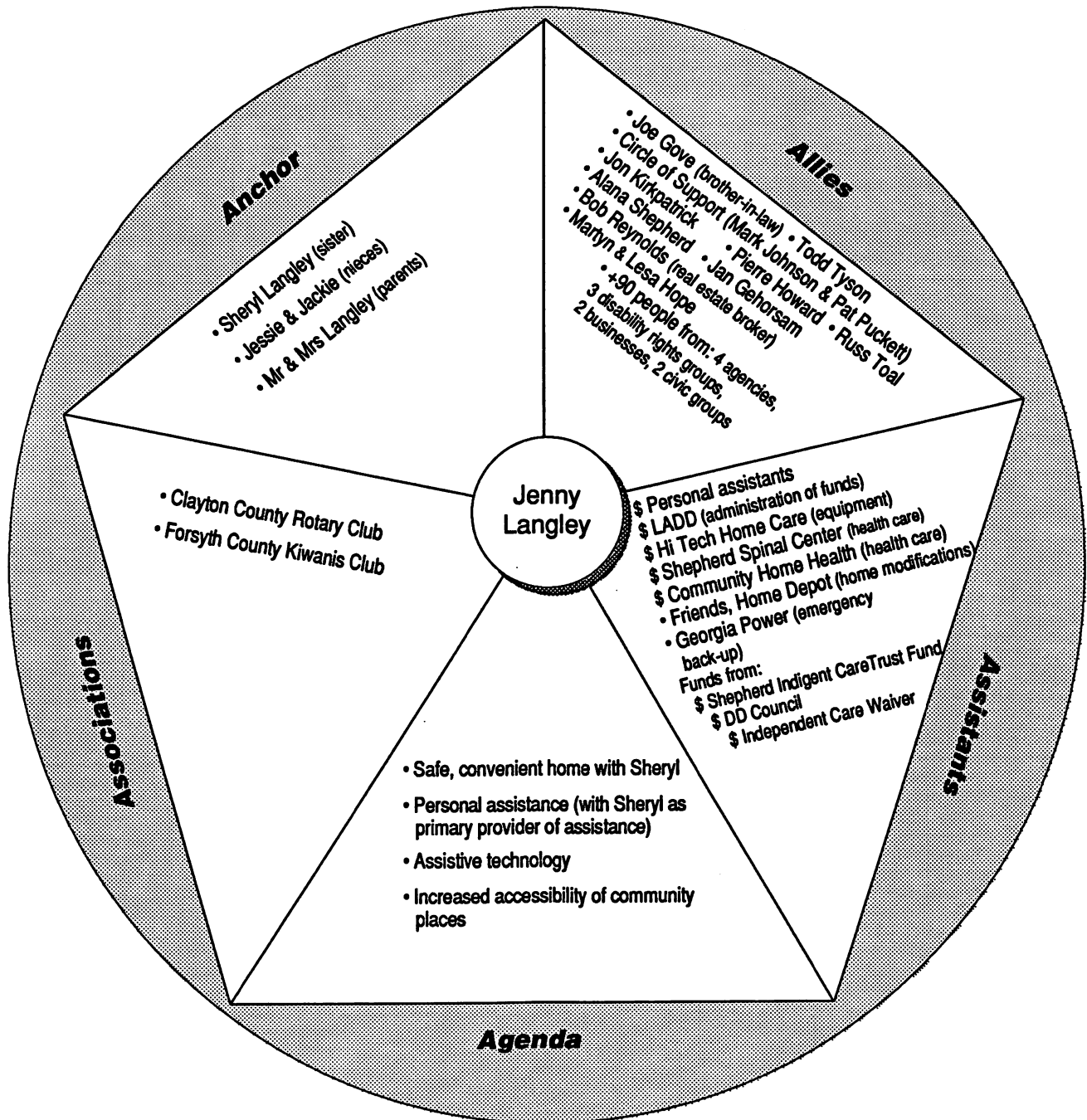
The diagram on the facing page identifies some of the people that have committed themselves in different ways to supporting Jenny Langley's choice of a desirable future and the agenda they have agreed to pursue together. The next page identifies some of the people who have committed themselves to Fred Pinson's choice of a desirable future and their agenda.

Thinking about the eleven people related to the study in terms of these commitments teaches some important lessons.

- Some people with disabilities in Georgia are rich in commitments from anchors, allies, and associations.
- Anchors, allies, and ordinary community members provide much (if not most) of the everyday assistance for many people. Their participation is more difficult because they have to cope with policies and practices that make it harder for people to get what they need.
- Some allies invest a great deal of time and energy, and people value some others as allies because they do things that might seem small to the ally but offer important validation or assistance in removing a barrier.
- The agendas that people develop with their anchors and allies are at odds with most federal and state long term care policies and funding priorities. The people I met want their own homes,

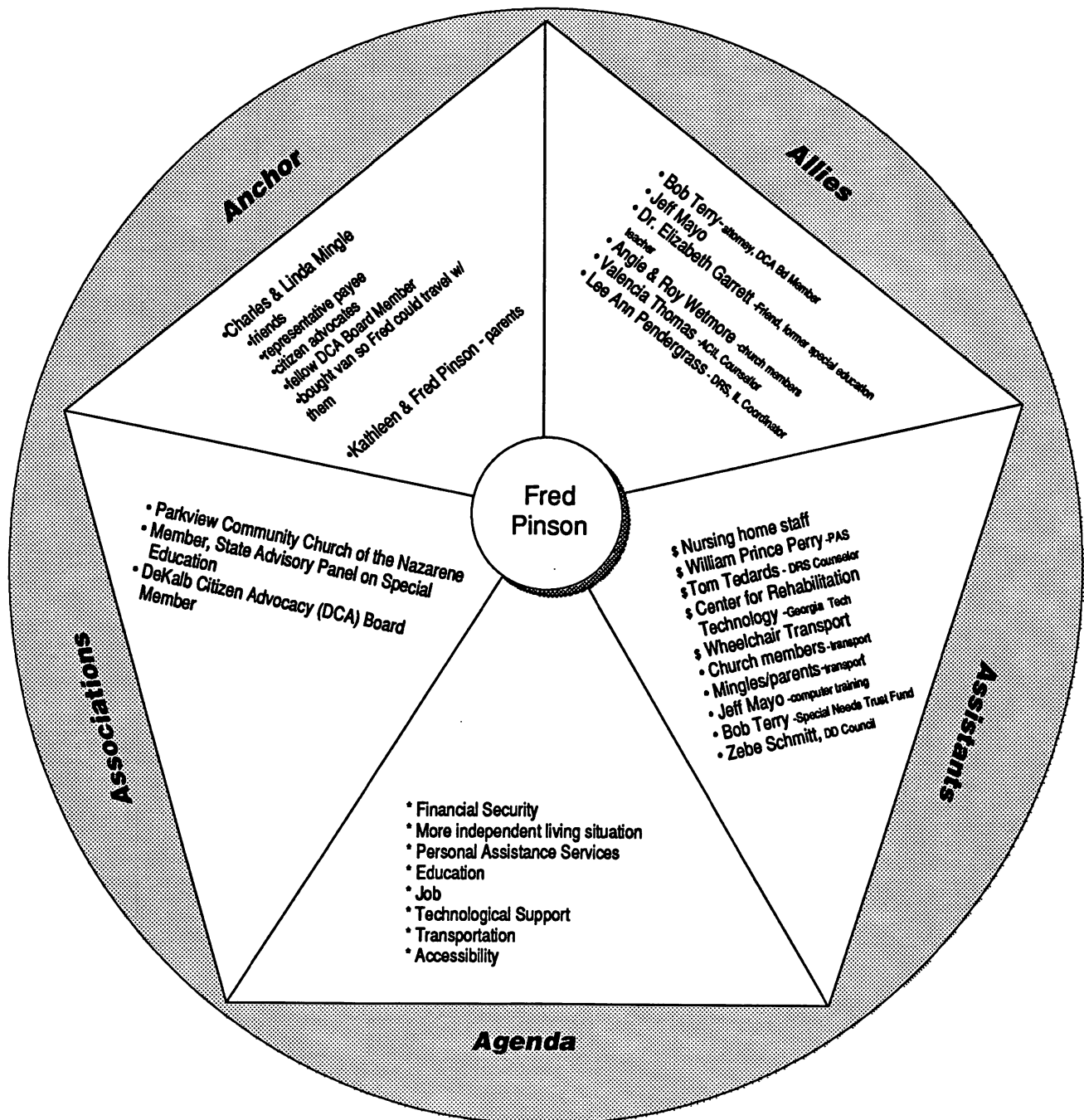
- To live with my family so I can watch my nieces grow up.
- To be an advocate & spokesperson for people with disabilities.
- To continually teach people by being present, involved, & active in my community.
- To sit in the sun in the back yard.
- To watch my boyfriend play piano & listen to music.

Desirable future



- Own apartment with roommate who could function as back-up attendant.
- Paid Personal Assistance Services (possibly 24-hour/day).
- Formal training as a computer programmer and a job.
- Accessible transportation.

Desirable future



personal assistance services, financial security, jobs, education, technological support, good health care, transportation, and accessible communities. State and national policies invest most of the public's money in nursing homes, hospitals, and institutions and define most personal assistance as a form of health care.

- Requirements for receiving assistance are unhelpful and some can destroy individual dignity, responsibility, and self-worth, family unity, and community involvement.
 - The current system leaves the person and family to flounder until they are overwhelmed and no longer able to care. Lack of paid support wears people down. When people can't continue the service system steps in and takes over.
 - The current service system ignores family contributions. But when family members wear out and give up, they may be treated as pitiable, personally weak, or dysfunctional. It is more useful to notice that the problem could also be identified as a lack of paid assistance that could complement the family's, person's, or community's contribution.
 - Jenny and Fred both have strong involved families. Their parents have been their anchors and assistants for many years. In Jenny's situation, lack of appropriate, paid assistance wore her mother down and reduced the entire family to poverty. Jenny became homeless and poor as well as physically disabled. Fred lived with his family until he was twenty-two then became too heavy for his parents to continue his care without help. They searched for alternatives, but the only thing they could find was a nursing home.
 - Jenny's and Fred's parents are still there for them, but the anchor commitment is now shared— Jenny's with her sister Sheryl and her family: Fred's with Charles and Linda Mingle, citizen advocates and friends. Jenny is one of a few people now able to benefit from a new form of assistance under the Independent Care Waiver. She has her own home with support. Fred has not been so lucky. His only option is still a nursing home.
 - All Georgia programs funded by Medicaid have individual (or couple) income and asset limitations. A person must be poor to get help. If you are not poor, you have to spend what you have and become poor. Some programs like CCSP and the Independent Care Waiver do allow for a cost share for people whose incomes or assets are too high to receive services free of charge. The cost share is prohibitive to some people.
 - Every person I met wants to work for pay. No one I met has a paid job. People are in a serious bind. The people I met are deemed unemployable even by the service system which is responsible to assist people with disabilities to find and keep a job (but not by themselves,

their friends, and allies!).

- If a person does find a job, the next problem arises. How much can I make without losing some or all of my assistance? Should I lie or cheat? Do I just lay back and be taken care of and feel worthless, and be seen as a burden by the tax-paying public?
- The most effective assistance now available in Georgia comes from a funding source with a time limit. This does not fit the facts of life for any person I met. Everyone will need continuous, life-long assistance, but dollars from the Indigent Care Trust Fund have carried a one-year limit; DRS Independent Living program funds have a three year limit; Medical Assistance Waiver programs must be re-negotiated every three to five years.
- Most paid assistance is tied to a facility or treatment mode and the schedules and routines are set by an agency or organization, not the person. People who need more than minimal personal assistance go to a nursing home because that is the only place 24 hour "specialized" care is available. If you are in a particular type of facility, you get what it offers whether you need it or not. If the facility doesn't provide it, you don't get it whether you need it or not.
 - Fred, who has to live in a nursing home because it is the only place he can get 24-hour support, has to get up at 5:00 am or 10:00 am. Nothing in between. Those are the times someone is available to get him out of bed.
 - Fred and his advocate Charles worked long and hard and had to file a grievance for to allow Fred to eat cookies in bed. The nursing home was worried about liability if he choked.
 - Fred's telephone is connected to the computer that Charles and Fred's family helped Fred to get. Fred operates his computer from his wheelchair. He telephoned one day to say that he would not be able to call the next day as we had arranged because his wheelchair was away being repaired. He only has one. If he's not in his chair, he can't use his computer. If he can't use his computer, he can't use the telephone.
 - Shane, who is living at home with limited amounts of Home Health Services has to go to bed by five on the days his attendants put him to bed because they work a 9:00 am to 5:00 pm day.
- Most assistance is tightly linked to medical treatment and requires recipients to accept being seen and treated as "sick" and needing medical or para-medical supervision of the details of their daily lives. This might make sense if any of the conditions that people live with could be "cured" or "fixed" within the foreseeable future, but that is highly unlikely for the people I met.
- Even if a person requires more than usual amounts of medication, or procedures usually thought of as medical, there should be a way to get and stay healthy without a person's whole life being defined by doc-

tors, nurses, or therapists. For example, state plan Home Health Services are only available to people who are "homebound." Both Wayne and Shane receive limited assistance only from this source. When Wayne decided to join AA to stop drinking and Shane returned to school, both became technically ineligible for the only service available. The only alternative source of assistance, the CCSP waiver, has 189 people ahead of them on a waiting list. Should Wayne stop going to AA? Should Shane drop out of school?

- Because necessary personal assistance is commonly, but mistakenly, understood as health care, there is a potential risk that people's assistants (including family members) could be considered to be violating laws and regulations governing professional practice simply by helping a person carry out daily health routines that non-disabled people would carry out for themselves, such as routine insulin injections, catheter care, and even taking prescribed medications. This has not yet been an issue in Georgia, but professional organizations in other states have lobbied for narrow and restrictive application of professional practice acts.

The people I met have recruited others to assist them and to ally with them to work for better lives. Most of Georgia's current long term care policies disregard or dishonor these commitments. The policies should change to bring paid assistance into alignment with the needs of people with disabilities.

Developing Georgia's Capacity to Provide A Real Choice

While there is room for a great deal of improvement in each of the six resources necessary to provide effective individualized support, two resources are most critically needed at this stage to develop the capacity required to provide severely disabled Georgians a real choice. Without effective personal assistance services, many people will be unable to maintain themselves in community life. Without people who can help plan, advocate for, and assist with problem solving, many people will be unable to establish themselves in community life.

Six Resources Necessary to Offer Individualized Support

Necessary help...

- ...to pay for and arrange necessary personal assistance services ✓
- ...to find, modify, and maintain suitable housing
- ...to choose to benefit from good health care
- ...to choose to benefit from adaptive technologies
- ...to travel from place to place
- ...to plan, advocate, arrange for, and solve problems to improve supports ✓

With these resources, people can pursue their own life choices concerning...

- ...occupation
- ...education
- ...personal relationships
- ...involvement in civic life

✓ *Most critical shortages in Georgia today.*

Personal Assistance Services

There is good news for Georgians who require effective personal assistance to maintain their life in community. Over the past four years, both the Department of Medical Assistance and the Department of Human Resources have developed programs that offer personal assistance services that are better aligned with what people with disabilities and their families need and want. Unfortunately, the more positive of these efforts –the Independent Care Waiver, the DRS Personal Assistance Program, and Georgia Options– are minuscule in size when compared to the investment in less effective, more restrictive

programs and compared to likely need.

Furthermore, these positive programs are embedded in large, complex systems which have been designed and are managed from facility-centered rather than individual-centered assumptions. To realize their promise, these tiny programs have to maintain their integrity and positively influence the systems that contain them: the rest of the system will first have to allow them to operate as they were designed and then change itself as it learns from them. This replay of the conflict between David and Goliath will require levels of leadership investment far out of proportion to the size of the programs.

Personal assistance services (PAS)

One or more people assisting another person with tasks which that person would do if not disabled. PAS include performing such tasks as...

- Dressing, bathing, eating, using the toilet (including bowel, bladder, and catheter assistance), getting in and out of one's bed or wheelchair, and ordinary assistance with breathing equipment
- On the job assistance
- Shopping, cooking, and cleaning house.
- Driving and routine vehicle maintenance
- Cognitive assistance with tasks like planning the day, maintaining routines, and managing money
- Assistance with communication through interpreting and reading and facilitating involvement in activities

To analyze Georgia's personal assistance options, I identified a set of 35 criteria¹ that appear to define the current state-of-the-art in personal assistance services. I established these criteria by consulting the people involved in this study and by reviewing the relevant literature.² I then asked people responsible for the five programs that offer personal assistance services in Georgia to complete a questionnaire which asked them to rate themselves on

¹ For definitions of each of these criteria, and the actual questionnaire responses of the programs reviewed here see Appendix B. For brief narrative descriptions of the programs, see Appendix C.

² I found the best understanding of personal assistance services in *Attending to America: Personal Assistance For Independent Living*, (1987), *Demand for Personal Assistance*, (1988), *The Need for Personal Assistance*, (1990), *Personal Assistance Services: A Guide to Policy and Action*, (1991), *Principles from Resolution on Personal Assistance Services* (1992), all by WID, Oakland CA: *Recommended Federal Policy Directions on Personal Assistance Services for Americans with Disabilities*, (Oct. 1991) by Consortium of Citizens with Disabilities.

the criteria and to briefly describe any variances between the criteria and their program. The table on the following pages summarizes the results.³

My preliminary investigation of personal assistance services in Georgia suggests:

- Most of the desirable features of effective personal assistance services are reflected in at least one Georgia program. In general, the newer the program, the more of the criteria it reflects.
- The most important exceptions to the criteria of effectiveness appear to concern:
 - The availability of personal assistance services to people who are not poor, to older people, and to children. This matters most when the importance and application of PAS to older people is taken into account. Many people who become disabled in old age find themselves in nursing homes “spending down” their life savings because there are no effective personal assistance services to assist them in staying in their own homes.
 - The capacity to pay family members, according to an individualized plan, for some of the assistance they provide.
 - The effects of receiving personal assistance services on employment, earnings, and eligibility for other benefits.
 - The option of participants accepting complete responsibility for training their assistants
 - The pay and benefits and career supports available to personal assistants.
- Only a very small number of people can benefit directly from the programs that have the most desirable features. Most people face the situation described like this by a DRS Independent Living Counselor, “Most people just have to get really motivated and learn to make do with hardly any help unless they want to go to a nursing home.”
- Georgia’s long term care system has the opportunity to learn from the implementation of small programs that, by design, embody most of the desirable features of effective personal

³ Two cautions about the judgments in the table. 1) The Independent Care Waiver and GA Options are just beginning operation as this is written. 2) Because these are self evaluations of program designs by program administrators or program developers, the table doesn’t necessarily reflect the actual experiences of people who use the programs.

Criteria	Independent Care Waiver	CCSP	MR Waiver	DRS PAP	GA Options
Serves people with all types of disabilities based on functional need.					
Serves people of all ages		•	•		•
Program funded through stable, long term source (partial = waiver program)	•	•	•		•
Type & amount of services defined by individual planning process which includes the participant.	•	•	•	•	•
Includes personal services	•	•	•	•	•
Includes household services	•	•	•	•	•
Includes assistance with infant & child care					
Includes life skills support	•				•
Includes communication services					•
Includes security enhancing services	•	•			
Includes mobility services both in and outside of home	•			•	•
Includes service coordination					•
Includes assistive technology	•				•
Includes emergency services					•
Both domestic & personal care (including catheterization & tracheostomy management) available from same program	•			•	
Does not restrict assistants from administering medications, routine injections, or managing catheter or tracheostomy				•	
No medical supervision is required	•			•	•
Assistance is available up to 24 hours/day if needed (partial = more than 20 hours/week)	•			•	•
Natural supports encouraged & supplemented; not discouraged or supplanted	•	•	•	•	•
Participant can receive cash or voucher to hire & supervise self-employed individual providers				•	

Criteria	Independent Care Waiver	CCSP	MR Waiver	DRS PAP	GA Options
Family members can be hired as individual providers	●				
Participant can use agency as fiscal agent/employer of assistants but retains control of hiring, training, supervision & firing				●	●
Participant can specify training required by assistants; no other training is required.					
Participant can choose to use assistants employed, trained, & supervised by agency		●	●	●	
Assistance available 7 days a week, at any time of day or night required	●			●	●
Assistance available on visiting, live-in, respite, emergency, or short term basis		●	●		●
Assistance is available for a variety of activities/settings: home, work, school, recreation, travel, political activity, etc.					●
There are no income eligibility requirements. (Partial = maximum allowable income at least 300% of poverty level)	●				
People with incomes over 300% of poverty level share costs of services	●	●			
No user required to pay more than 2% of net income after deduction of disability related expenses.					
No resource test applied to non-income assets of eligible participants				●	●
Payments to participants not regarded as disposable taxable income & thus do not make participants ineligible for other benefits & services					
Participation in program does not create disincentives to employment				●	●
Personal assistants receive reasonable pay & benefits					
Program provides a process to mediate conflicts between assistants & employers & deal with assistant grievances.					●

assistance services. If the system can learn from its best efforts, the system will develop the quality of service as it expands the numbers served.

- To realize this possibility, it is essential that these small, new programs maintain their desirable features as they are implemented and expanded. This means that they will need continuing leadership from the committed champions within DMA and DHR and the external advocates who collaborated to design them. These champions and advocates need effective ways to continue to work together through the implementation phase. They will face at least four challenges:
 - The demands generated by the crushing scarcity of assistance across the state will create a pressure to expand and dilute the program's focus.
 - Like any innovation, these programs themselves will have to learn how to do what they have promised. They will not be even close to perfect, especially after the initial energy of the foundation period runs down. We can expect them to teach the rest of the system about how to produce new outcomes; we can't expect them to be error free. We are, as one administrator put it, "Kind of like Indiana Jones: we have to make it up as we go along."
 - Historically, the system has dealt with people who have been able to exert substantial political pressure by creating small, encapsulated exceptions. If programs like Georgia Options and the Independent Care Waiver are to effect the whole system, they will need extra resources to support the dissemination of their learning.
 - The intentional mis-match between these programs and "business as usual" will create a) many, many bureaucratic misunderstandings and confusion that will threaten the quality of implementation; b) the possibility of opposition from providers of nursing home and home health care, most likely in the form of an attempt to take the new programs over.

Advocacy & Assistance with Problem Solving

All of the people I met whose lives are improving benefit from a unique blend of advocacy and assistance with problem solving. This approach combines...

...support in bringing a person together with his or her allies to define and work for what the person really wants instead of

settling for what they think they can get from the system as it is

- ...help for people considering a change to make links to other people whose living arrangements provide a practical model of what is possible
- ...practical help in figuring out specific needs for assistance, budgets, schedules, and tactics for recruiting, training, and supervising assistants
- ...knowledge of ways to influence the system to gain the resources the person needs
- ...ways to involve people in collective action to change policy and social attitudes.

The power of this approach results from people with the independence, knowledge, skills, and networks of contacts to combine these functions in their relationship with people who want a change in their lives. This allows them to help people address the problems they face at all of the different levels where they occur.

Many people with severe disabilities, and many family members, want to become more deeply involved in assisting others in these ways. It is imperative to support the work of committed, skilled activists and their efforts to increase their numbers.

A Scenario for Development

The figure on the next page sketches one possible sequence for development of Georgia's capacity to offer all people, regardless of disability, a real choice between individualized support and nursing home, hospital, or institutional care. It assumes that:

- Georgia is now in the earliest stages of development, with real but small strengths.
- The system can learn from existing Georgia efforts, and from other states with a longer history (like Wisconsin, California, Colorado, and Pennsylvania) to support movement to a transition phase in which individualized support alternatives will scale up.
- Enough Georgians are concerned about this issue to respond to organizing efforts and to build the political will to allow the large scale development of alternatives.
- Federal long term care policy will offer sufficient flexibility to

I
Nursing homes dominate

II
Alternatives develop

III
A fair chance for individualized supports

Now



- Growing dissatisfaction with outcomes & costs of existing nursing home & home care services.
- Increasing awareness of better ways to assist people, mostly discovered through personal contacts.
- Small & growing efforts to organize people and families to assert their right to alternatives to services which control & contain people.
- A few people & their families experiencing better support, through great effort to stretch existing programs/policies & big investment of time & risk by person, family, friends, & activists.
- Policy of allowing very small and well contained exceptions in response to specific pressures through tightly defined & controlled waivers.
- Tiny proportion of available funds invested in alternatives to nursing homes.

- Clear, public policy of developing individualized supports so that increasing numbers of people will have a real alternative to nursing home or hospital.
- Cash investment in individualized supports growing from 2% to 25% of total annual public expenditures on long term support.
- State agency leadership investment in minimizing barriers to new program development & maximizing flexibility & variety of individualized supports.
- Emergence of user controlled agencies dedicated to the provision of individualized supports.
- Efforts to organize people and families strengthened by growing numbers of people with the freedom to join in advocating for themselves and others.
- Shared efforts to learn by evaluating outcomes & costs of both nursing homes & individualized supports.

- Given favorable outcomes for individualized supports during the developmental phase, public policy offers each person a choice between individualized supports & living in a nursing home.
- Increasing annual investment from 25% of annual public expenditure on long term support to a proportion that reflects actual demand for individualized supports.

allow development of alternatives for substantial numbers of people of all ages and with all levels of disability.

Priorities for action

- Policies and public expenditure on personal assistance services are the least developed system resources necessary to insure the development of a long term care system that offers people a genuine alternative to nursing home care.
- Individualized supports are a real alternative to current policies (apart from the Independent Care Waiver), not just an add-on to the present system. Individualized supports embody different ways of thinking about people with disabilities, different sorts of organizational designs, job roles and procedures, and different kinds of management. Effective and sufficient personal assistance services cannot develop without vigorous advocacy and strong agency leadership to overcome the biases which have accumulated in the present system.
- Policies and public investments in affordable, accessible housing will benefit a number of people who need individualized supports.
- More people need opportunities to join people with disabilities and their families to plan and implement individualized supports and to develop local agencies with the capacity to provide assistance. Current efforts by Creative Pathways, LADD of Metropolitan Atlanta, and Georgia Options provide a beginning. Their work needs encouragement and assistance to allow people in other parts of the state to learn from them. Others with different ideas of how to organize individualized supports need opportunities to try.
- Given information about alternatives and a chance for change, it is likely that a substantial number of people now in nursing homes and hospitals would choose individualized supports. Independent efforts to reach-in to nursing homes need development.
- Well organized advocacy by people with disabilities themselves is vital to developing an effective long term care system. Organizing work by Shepherd Spinal Center, Georgia ADAPT, and Concrete Change provide an important beginning. Many people with severe disabilities are unable to join advocacy efforts because the current system traps them at home or confines them in nursing homes.

- Current development of individualized supports results from an international movement among people with disabilities and a parallel set of state and national initiatives by policy makers and service providers concerned to make effective use of public funds. Efforts to re-design Georgia's system will benefit from strong links with others working along similar lines.

Recommendations for Action by The Governor's Council on Developmental Disabilities

I. Council Action

1. Support positive changes recommended or instituted by Department of Medical Assistance (DMA)

- Support efforts by DMA to include services which now can only be offered by applying for a waiver [Independent Care, Georgia Options, Community Care Services Program (CCSP)] as optional state plan services. This would eliminate cumbersome application and renewal process.
- Support DMA's request for expansion of the Independent Care Waiver in the '94 budget requests (expansion to include wider geographic area and more people).
- Support DMA's new Implementation Team for Independent Care Waiver.
- Support DMA's new Task Force on Indigent Care Trust Fund (members to be selected by July 15, 1992).
- Encourage DMA to include people with disabilities as participants in the revisions of CCSP waiver and other programs which are designed to provide assistance to people with severe disabilities.
- Include a representative from the State Health Planning Agency on Council (or at least on a committee that involves issues around supported community living and personal assistance services).

2. Build collaborative relationships with advocates for elders including Office on Aging, AARP, and other groups that share interest in individualized supports and individual choice to increase options available outside nursing homes, hospitals, and institutions for people who require long term care.

3. Develop Leadership

- Nominate consumer member of council as representative to newly formed Implementation Team for Independent Care Waiver.
- Nominate a member to the Task Force on Indigent Care Funds is being established by DMA.

- Ensure that active people with disabilities, including those who participated in this study and those who attended the Macon meeting, know how to apply for Council funds to assist with tuition's, transportation, personal assistant services hourly reimbursement, food and hotel costs to attend and participate in meetings, hearings, committees, training events.

4. Purchase and widely distribute copies of *Entryways* by Eleanor Smith, which tells builders and property developers how to improve accessibility of new and existing housing.
5. Broaden the coverage of the Council's *People First* newsletter to include disability rights issues by establishing an Editorial Board which includes representatives from various disability rights groups.
6. Work to ensure that people with developmental disabilities who do not have mental retardation are eligible for the same services as people with mental retardation.
7. Explore ways that money currently being spent on long term care could be reallocated to be more closely aligned with the preferences of people with disabilities (For example: ADAPT supports an initiative to reallocate 25% of money currently going to nursing homes into home and community based services. Other ways to use existing money also need to be explored).

II. Action by Council Staff or Consultant

1. Learn about and keep up with changes and innovations in Medicaid and long term care policy in Georgia and nationally
2. Disseminate above information widely to parent groups, disability rights groups, state agencies, and other interested individuals or groups
3. Learn about and disseminate innovations across Georgia and from other places

III. Requests For Proposals (RFP's):

1. Establish a Community Supported Living Network focusing on issues around individualized support including...

...Personal Assistance Services (in collaboration with the Personal Assistance Services Resource Network)

...Housing (Continue connection made with Daphne Smith, SE. Regional Director of Habitat for Humanity in Americus who attended Macon meeting; Concrete Change has had substantial success in Atlanta with requiring accessibility in existing and new housing)

... Access to good quality health care

...Transportation

...Problem solving

- Provide opportunities for people with disabilities, their family and friends to expand their vision of what is possible
- Support training efforts to bring in people from across the country who are already working on and have longer term experience with Community Supported Living.
- Support learning opportunities for person with a disability and/or family members, allies around specific issues such as: Demedicalization of personal supports and assistance; individualized supports; and strategies for change.

2. Establish a Disability Rights Leadership Project to:

- Build a self-advocacy network to create and nurture partnerships between disability rights groups.
- Develop, publish, and support a state-wide agenda from Disability Rights Groups (People First, Georgians for a Common Sense Health Plan, ADA Exchange, ADAPT, Let's Get Together, Concrete Change, and others as identified).
- Work to expand coalition to other groups interested in personal assistance services (National AARP, Local groups like interested Offices on Aging).
- Identify people to participate in Partners in Policy network.
- Reach out to uninvolved people, recruit to expand network (should include follow-up with people who were invited and/or attended Macon meeting at Christ Church).
- Identify and support people with disabilities who are willing, if paid for time and expenses, to go into nursing homes & talk directly with people with disabilities who might want to live elsewhere with support but don't know there should be an option.
- Develop, expand, maintain, & distribute a mailing list of people interested in action on long term care policy.

- Get information on real choices out to people (includes sharing of information gathered for this report).
- Convene local groups to discuss local, state, and national issues.
- Get people to meetings, hearings, training, and political events.
- Learn about and keep up with Medicaid policy.
- Learn about and disseminate what is going on in other places.
- Watch-dog Georgia developments for tendencies to over-regulate, over-medicalize, and otherwise restrict new and positive developments like Georgia Options, Independent Care Waiver, Community Care Support Program.
- Take advantage of up-coming opportunities to make changes in current programs: e.g. the CCSP waiver is coming up for renewal and the DRS Independent Living Program could be expanded with funds that are more stable and long term than the current Indigent Care Trust Funds.

3. Establish a non-profit organization in at least one geographically manageable area to demonstrate effective ways to find, train, and support providers of personal assistants and other people resources necessary for supported community living.

- Locate and evaluate existing training materials and produce a basic training video for attendants, family members.
- Develop strategies, conduct problem-solving sessions to help people with disabilities, their anchors and allies explore issues beyond basic care which are vital to people's long term well being as a self-managing employer. For example...
 - ... importance of person with a disability knowing what she needs and being able to confidently & accurately request it.
 - ... dealing with trade-offs that come with life long necessity for medications to maintain health and well being
 - ...finding out about, understanding, and managing benefits such as direct payments to person; tax and record keeping requirements; health insurance
 - ...how to involve the private sector and ordinary citizens
 - ...maintaining balance between supporting but not replacing natural supports and networks.

- Explore insurance options for family members or other people providing personal assistance. Some family members lose insurance coverage for themselves when forced to leave a job to stay home and support a family member with a disability; individuals who provide personal assistance services as individual providers also have limited access to insurance.

Appendix A

Indigent Care Trust Fund Department of Medical Assistance (DMA)

Created by an amendment to the Georgia Constitution, the Georgia Indigent Care Trust Fund began in fiscal year 1991 (July, 1990-June 1991).¹ The amendment authorized the General Assembly "to provide by general law for the creation of an Indigent Care Trust Fund..." It authorized "any hospital, hospital authority, county, or municipality to contribute or transfer moneys to the fund." It further specified that the fund be used only for "primary health care programs for medically indigent citizens and children of Georgia, to expand Medicaid eligibility, or to support rural and other health care providers, primarily hospitals, who disproportionately serve people who are medically indigent." (H.R. No. 840 (SUB).

The Indigent Care Trust Fund is a program where hospitals which have been designated as "disproportionate share hospitals"² donate money to the state. That money is used as a state share of funds to be matched with federal funds. A significant proportion of the total state and federal money would go back to hospitals that contributed. In the first year, 57 hospitals donated \$35 million which generated \$55 million from the federal government. For fiscal year 1992, 68 hospitals were involved donating an estimated state amount of \$96.7 million that increases to \$253 million when the Federal match is added. For 1992, \$242 million would go back to the hospitals making the donations with \$11 million left over for DMA to use on other things.³

The state has few rules on how money returned to the hospitals can be spent. There is a requirement that 15% of the \$242 million returned to the hospitals must be spent for primary care services. Each hospital in the Fund must submit a plan for how it will spend 15% of the total money received from the Fund on primary care. The plan must be approved by DMA before the hospital receives the money. Hospitals are required to submit a summary report every six months showing how the money has been spent.

The first use of the Indigent Care Trust Fund to provide support in community living arrangements for people with severe disabilities was for Larry McAfee, a Georgian with quadriplegia, reliant on a ventilator for oxygen. McAfee was living in an Alabama nursing home because nursing homes in Georgia refuse to take people who use ventilators. McAfee gained national attention in 1989 after a federal judge granted his request to die by being sedated and having his ventilator disconnected. After his request was approved, McAfee was approached, questioned, and supported by disability activists who joined his fight to return home to Georgia and have support available to live outside a nursing home. Following a lengthy political battle including an occupation of both the commissioner of DMA's office and the Governor's office by Atlanta disability activists, the Governor directed the Commissioner to find a place for McAfee to live.⁴ A pilot program in Augusta was set up using Indigent Care Trust Funds.

¹ Description comes from Georgia DMA Annual Report 1991 and personal interview with Gary Redding, Assistant Commissioner, DMA (March 19, 1992)

² Hospitals that serve a "disproportionate number of low-income patients with special needs". To be designated as a disproportionate share hospital, a hospital must meet at least 1 of 8 criteria outlined in Part II Chapter 1000 (Revised July 1991) of Policies and Procedures for Hospital Services, DMA, Revised Nov. 1988).

³ DMA, Indigent Care Trust Fund, Calculations for SFY1992 donations, Feb. 21, 1992

⁴ Puckett, Pat. (1992). *Personal Assistance Services in Georgia, 1992 Status Report*. Stone Mountain, GA.

Activists continued their efforts to move both the federal and state governments to provide funding through Medicaid for Personal Assistance so that people with severe disabilities would have support that would include an alternative to a nursing home. In 1990, Georgia DMA requested \$261,000 dollars in state funds to support 24 Georgians, but the Governor did not recommend funding. In the spring of 1991, the Georgia Legislature appropriated \$100,000.00 for the Independent Care Program and \$50,000.00 for Personal Assistance under Rehabilitation Services. The Governor cut this out, but the legislature re-stored 60% of the funding. This cut delayed the possible start up time for the Independent Care program for several months.

Meanwhile, in the summer of 1990, based on knowledge gained while pursuing Larry McAfee's agenda, Georgia disability activists working in collaboration with Jenny Langley, her family, and Shepherd Spinal Center set up a one year pilot project for Jenny funded with part of Shepherd's Indigent Care Trust Fund primary care dollars. In September of 1991, Grady Hospital which had learned of the success of the Shepherd pilot, decided to use part of their primary care dollars to finance a one year supported living pilot program for two men, Charles Lewis and Charlie Grier, who had been living at Grady for over three years because no other alternatives were available. Use of the Indigent Care Trust Funds was seen as a way to support Jenny, Charles, and Charlie until the Georgia Independent Care Waiver was approved.

Jenny's living arrangement was put in great danger by the Governor's 1991 budget cuts. Instead of January, the earliest time for start up of the Independent Care Waiver became April and possibly May of 1992. Jenny faced a four or five month lapse of funding between the end of the Indigent Care Trust Fund financing and the beginning of the new Medicaid waived services program. A scramble to find additional money began, with activists requesting temporary assistance from the Governor's Emergency Fund. This did not succeed, but Russ Toal, Commissioner of DMA, worked to arrange a way to temporarily fund Jenny's support by getting money from the DD Council and the Division of Rehabilitation Services to bridge the gap in funding from Shepherd and the beginning of the new Medicaid waiver.

Creative use of Indigent Care Trust Funds by three hospitals on behalf of a few people has enabled a small number of Georgia citizens, their families, advocates and allies to prove that people with severe disability and need for 24-hour support, including ventilators for breathing, can live well in ordinary homes in the community if the funding of supports is adequate and flexible enough to accommodate the individual differences, needs, and preferences of each person. Use of these funds has supported people while DMA sought and received a Medicaid waiver that will now pick up the costs for a small number of people from a longer term source.

Though it may continue to play a part in funding the startup costs of innovations or provide short term funding for individuals in specific cases, the Indigent Care Trust Fund is not a substitute for an individualized support policy. **The Indigent Care Trust Fund cannot meet the long term support needs of Georgia's disabled citizens.**

Summary facts:

- The Indigent Care Trust Fund generated approximately \$253 million in 1992 with \$96.7 million contributed in donations by 68 hospitals which have been designated as "disproportionate share hospitals" and the rest drawn down as federal financial participation.
- A total of \$242 million was returned to the 68 hospitals. The remaining \$11 million is available to DMA for other purposes.
- The state requires that 15% of the money returned to a hospital be spent on "primary care." Hospitals

must submit a plan to DMA for how it's "primary care" funds are to be used. DMA must approve this plan before a hospital receives any of the funds. No more than 50% of the required primary care dollars can be spent on capital construction or equipment. (As of Mar. 19, two hospitals, Grady and Columbus Medical Center have been granted exceptions to this 50% rule.)

- There is no requirement for public input into decisions about how any of these dollars are spent by the hospitals. DMA requests that hospitals have the District Health Director review the plans and give their endorsement before hospitals submit the plan to DMA. After the plan has been approved, hospitals are asked to publish a notice that the funds are available and what they are available for so that people who are indigent can make use of them.
- As of October, 1992, states will no longer be able to use a donations program like Georgia's Indigent Care Trust Fund as a source of matching dollars to claim federal financial participation for Medicaid program costs. This is the result of a major battle between the President and Congress and the states and the Health Care Financing Administration (HCFA) that has been waging since 1987 when President Reagan first began efforts to limit the use of privately donated or voluntarily contributed funds as a state's share of Medicaid. During the summer of 1991, controversy grew when the President's Office of Management and Budget (OMB) proposed new rules that would eliminate the use of non-state dollars as matching funds for federal financial participation. OMB's reasoning was that the states had found ways to give Medicaid dollars to health care providers without increasing the state's contribution. The latest resolution of this ongoing dispute came in a decision over a substitute version of H.R. 3595 that was ratified by the House and Senate on November 27, 1991 minutes before Congress adjourned. It provides that all future matchable state revenues must be derived from taxes that are uniformly applied to all health care providers within a specific provider class. States are prohibited from guaranteeing or agreeing to return a portion of these tax revenues to Medicaid providers.
- As of my March 19, 1992 meeting with Gary Redding, Assistant Commissioner of DMA, the state had not decided what will replace the current Indigent Care Trust Fund. On June 22, Redding told me there will be an amendment on the ballot in November, but details are yet to be worked out.

*For an account of this on-going debate, see NASMRPD Newsletters dating from Sept. 1991 through Dec. 10, 1991. The Dec. 10, Intelligence Report, Bulletin #91-98 details above outlined results. See also Gary Smith and Robert Gettings (1992), *Medicaid in the Community: The HCB Waiver and CSLA Programs*, Federal Funding Inquiry, NASMRDD, Alexandria, VA., pp. 39-40).

Appendix B

Self Evaluation of Georgia's Personal Assistance Programs

This appendix reproduces the self-evaluations provided by people knowledgeable about five personal assistance programs.

Definitions:

- **Personal services** (including, but not limited to, those appropriate for carrying out activities of daily living in or out of the home (assistance with bathing/personal hygiene, bowel and bladder care, including catheterization, dressing and grooming, lifting and transferring, eating (including feeding), giving medications and injections, menstrual care, operating and maintaining respiratory equipment and the provision of assistive technology devices and services.)
- **Household services** (including, but not limited to, assistance with meal planning and preparation, shopping, light housekeeping, laundry, heavy cleaning, yardwork, repairs and maintenance)
- **Child and infant care assistance** for eligible persons with disabilities who are the parents of children under the age of 18 meant to assist them in carrying out the functions of parenting (e.g. assistance with diapering, feeding, lifting or transporting a child)
- **Life skills support services** (including, but not limited to, assistance with money management, planning and decision making including computer assisted directions, home management, use of medications, following instructions, positive behavior management, companion or roommate services which provide regular supervision up to 24 hours for daily living, peer support, advocacy, and support for participation in social, community or other activities. Life Skills Support Services assist the individual to acquire, retain, regain, improve, or execute the self-help, socialization, decision making and adaptive skills necessary to achieve and maintain independence, productivity and integration and to live successfully in his/her home. These services can include training, prompting, cuing, support or substitute functioning.)
- **Communication Services** including, but not limited to, assistance with interpreting, reading, letter writing, and the use of communication and/or telecommunication devices.
- **Security-enhancing services**, including, but not limited to, monitoring alarms or systems and making or arranging for periodic contact in person and/or by phone.
- **Mobility services in and out of home**, including, but not limited to, escort and driving, mobility assistance including on use of public transportation.
- **Service Coordination** including assistance with recruiting, screening, referring and managing personal assistance.
- **Assistive technology services**, including assistance with evaluating the needs of an individual in his or her every day environment; purchasing, leasing or obtaining assistive technology devices for use by individuals with disabilities; selecting, designing, fitting, customizing, adapting, applying, maintaining,, repairing or replacing such devices; coordinating and using other therapies, interventions or services with AT devices (e.g. those associated with existing education/rehabilitation plans or program); training or technical assistance for an individual with disabilities or where appropriate the family; and training or technical assistance for personal assistants.
- **Emergency services**, including substitute services for any of the above services needed on an emergency basis.

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

Name (type) of program being rated: Independent Care Services
 Administered by: Department of Medical Assistance
 Provided by: _____

Date: 6/11/92

Check each statement that is true of the program you are rating. For each statement that is not checked (does NOT describe an accurate feature of the program being rated), please write in what is accurate about the program being rated in relationship to the statement.

#	Desired design criteria	Current actual design criteria of program being rated
1. <input type="checkbox"/>	Program serves people with all types of disabilities on the basis of functional need.	<u>Individuals with severe disabilities</u>
2. <input type="checkbox"/>	Program serves people of all ages.	<u>Serves individuals from 21 years of age and older</u>
3. <input checked="" type="checkbox"/>	PAS include, but are not limited to: (see definitions at end for complete description of each service listed) <ul style="list-style-type: none"> <input checked="" type="checkbox"/> personal services <input type="checkbox"/> household services <input type="checkbox"/> child & infant care assistance <input type="checkbox"/> life skills support services <input type="checkbox"/> communication services <input type="checkbox"/> security-enhancing services <input type="checkbox"/> mobility services both in & outside of home <input type="checkbox"/> service coordination <input type="checkbox"/> assistive technology <input type="checkbox"/> emergency services 	<u>other services</u> ① <u>Homemaker Service - Household Chores</u> ② <u>Companion Service - Assist with life skills support</u> ③ <u>PERS - Emergency Response System for emergency services</u> ④ <u>Specialized Medical Equipment - includes adaptive equipment</u> ⑤ <u>Transportation - provides mobility services outside of home.</u>

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
4. ____	No medical supervision is required.	<i>Supervision is required for personal care, companion & homemaker services but is non-medical</i>
5. <input checked="" type="checkbox"/>	Both domestic and personal care services (including catheterization & tracheostomy management) are available from the same program.	
6. ____	The program does not restrict individual providers from administering medications or injections or from carrying out catheter or tracheostomy management.	<i>medication administration is limited to skilled nursing only. Assistance with administration of oral medications is permitted by other disciplines.</i>
7. ____	There are no maximum limits on hours of utilization (mark with a circle if there is a maximum but it is greater than 20 hours per week).	<i>There are no maximum limits on utilization except for the following services: ① P.E.K.s; ② Environmental Modification ③ Specialty Medical Equipment</i>
8. <input checked="" type="checkbox"/>	Natural/informal supports are not supplanted or discouraged by PAS but are encouraged and supplemented by PAS so that natural supports are available to PAS user in the same way they are available to all citizens.	

**Personal Assistance Services
PAS
Desirable Design Criteria checklist**

#	Desired design criteria	Current actual design criteria of program being rated
9. <input checked="" type="checkbox"/>	<p>User* has a choice of type of service provider, hours of availability & location of support:</p> <p>The following choices are available:</p> <ul style="list-style-type: none"> <input type="checkbox"/> • person receives cash or voucher to hire self-employed individual providers including family members, employed & supervised by the user. <input type="checkbox"/> • person has control of hiring, firing, training, supervising individual provider but agency is actual employee (fiscal agent) <input type="checkbox"/> • agency providers employed and supervised by a private or public agency. <input checked="" type="checkbox"/> • available on 24 hr./day, 7 day/week basis <input type="checkbox"/> • available on visiting, live-in, respite, emergency, and/or short term basis. <input type="checkbox"/> • available in a variety of settings & for a variety activities including but not limited to home, work, school, recreation, leisure, travel & politics. 	<p><i>Client assist in selection of individuals involved in care with the Case Manager. Supervision done by Case manager.</i></p> <p><i>Services provided in home.</i></p>
10. <input type="checkbox"/>	There is no income eligibility (mark with a circle if income is a criterion but maximum allowable income is at least 300% of the poverty level).	
11. <input checked="" type="checkbox"/>	For people with incomes over 300% of the poverty level PAS are offered on a cost sharing basis.	

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
12.____	No user is required to pay more than 2% of net income, after disability related expenses are deducted, on PAS.	
13.____	No resource test is applied to non-income assets of eligible people.	
14.____	Payments to users are not treated as disposable taxable incomes & do not make users ineligible for other statutory benefits & services.	
15.____	There are no employment disincentives to PAS.	
16.____	User can hire & fire the personal assistant.	
17.____	User can receive a direct cash grant & pay the personal assistant.	
18.____	User can determine the training requirements for personal assistants; none other is required.	

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
19. _____	Recruitment & training of personal assistants is available as needed.	<i>must be provided before becoming a service provider.</i>
20. <input checked="" type="checkbox"/> _____	User can participate in the assessment & planning process that determines the type of service & number of hours allocated to user.	
21. _____	Funding for PAS comes from a stable, long term source.	
22. _____	Personal assistants receive reasonable remuneration & basic benefits.	
23. _____	Program has a process to protect assistants including a grievance mechanism.	

* NOTE: Anywhere the work "user" is found, this applies to the person actually receiving/using a PAS and/or the person's legal representative or guardian.

Adapted from CCD, 1991; WID, 1987 & 1991; Ratrzka, 1986; Kapp, 1990)

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

Name (type) of program being rated: CCSP Community Care Services Program
 Administered by: Department of Mental Health + Office of Aging (DHAR)
 Provided by: Various Providers

Date: 6/12/92

Check each statement that is true of the program you are rating. For each statement that is not checked (does NOT describe an accurate feature of the program being rated), please write in what is accurate about the program being rated in relationship to the statement.

#	Desired design criteria	Current actual design criteria of program being rated
1. <input type="checkbox"/>	Program serves people with all types of disabilities on the basis of functional need.	<u>Geared primarily to the elderly</u> <u>by design</u>
2. <input checked="" type="checkbox"/>	Program serves people of all ages.	<u>There's no age requirement however, most</u> <u>services are rendered to the elderly.</u>
3. <input checked="" type="checkbox"/>	PAS include, but are not limited to: (see definitions at end for complete description of each service listed) <ul style="list-style-type: none"> • personal services • household services • child & infant care assistance • life skills support services • communication services • security-enhancing services • mobility services both in & outside of home • service coordination • assistive technology • emergency services 	1) <u>Homemaker Services (Household Chores)</u> 2) <u>Adult Day Rehabilitation</u> 3) <u>Emergency Response System</u> 4) <u>Personal Care Homes</u> <u>(Group and family model)</u> 5) <u>Skilled Services</u> <u>a) Nursing</u> <u>b) Home Health aide Services</u> <u>c) All Therapies (Speech, Physical & Occupational)</u> <u>d) Medical Social Services</u> 6) <u>Respite Services</u>

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
4. ____	No medical supervision is required.	<i>All services must be supervised by a nurse except ERS.</i>
5. ____	Both domestic and personal care services (including catheterization & tracheostomy management) are available from the same program.	
6. ____	The program does not restrict individual providers from administering medications or injections or from carrying out catheter or tracheostomy management.	<i>Medication administration is limited to skilled nursing only. Assistance with oral medication is permitted by other disciplines.</i>
7. ____	There are no maximum limits on hours of utilization (mark with a circle if there is a maximum but it is greater than 20 hours per week).	<i>While there are maximum limits for service provided, the cost cap for services capped at \$750.00 per month with prior approval</i>
8. <input checked="" type="checkbox"/>	Natural/informal supports are not supplanted or discouraged by PAS but are encouraged and supplemented by PAS so that natural supports are available to PAS user in the same way they are available to all citizens.	

**Personal Assistance Services
PAS
Desirable Design Criteria checklist**

#	Desired design criteria	Current actual design criteria of program being rated
9. <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>	<p>User* has a choice of type of service provider, hours of availability & location of support: The following choices are available:</p> <ul style="list-style-type: none"> • person receives cash or voucher to hire self-employed individual providers including family members, employed & supervised by the user. • person has control of hiring, firing, training, supervising individual provider but agency is actual employee (fiscal agent) • agency providers employed and supervised by a private or public agency. • available on 24 hr./day, 7 day/week basis • available on visiting, live-in, respite, emergency, and/or short term basis. • available in a variety of settings & for a variety activities including but not limited to home, work, school, recreation, leisure, travel & politics. 	Emergency Response Services
10. <input type="checkbox"/>	There is no income eligibility (mark with a circle if income is a criterion but maximum allowable income is at least 300% of the poverty level).	Clients must be SSI or share in the cost of services provided
11. <input checked="" type="checkbox"/>	For people with incomes over 300% of the poverty level PAS are offered on a cost sharing basis.	tives to PAS.

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
12.____	No user is required to pay more than 2% of net income, after disability related expenses are deducted, on PAS.	
13.____	No resource test is applied to non-income assets of eligible people.	
14.____	Payments to users are not treated as disposable taxable incomes & do not make users ineligible for other statutory benefits & services.	
15.____	There are no employment disincentives to PAS.	
16.____	User can hire & fire the personal assistant.	
17.____	User can receive a direct cash grant & pay the personal assistant.	
18.____	User can determine the training requirements for personal assistants; none other is required.	

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
19. ____	Recruitment & training of personal assistants is available as needed.	
20. <input checked="" type="checkbox"/>	User can participate in the assessment & planning process that determines the type of service & number of hours allocated to user.	
21. ____	Funding for PAS comes from a stable, long term source.	
22. ____	Personal assistants receive reasonable remuneration & basic benefits.	
23. ____	Program has a process to protect assistants including a grievance mechanism.	

Adapted from CCD, 1991; WID, 1987 & 1991; Ratrzka, 1986; Kapp, 1990)

* NOTE: Anywhere the work "user" is found, this applies to the person actually receiving/using a PAS and/or the person's legal representative or guardian.

Personal Assistance Services

PAS

Desirable Design Criteria Checklist

Name (type) of program being rated: *MRWP Mental Retardation Services Program*
 Administered by: *State of Mississippi Department of Mental Health*
 Provided by: *Various Providers*

Date: *6/12/92*

Check each statement that is true of the program you are rating. For each statement that is not checked (does NOT describe an accurate feature of the program being rated), please write in what is accurate about the program being rated in relationship to the statement.

#	Desired design criteria	Current actual design criteria of program being rated
1. <input type="checkbox"/>	Program serves people with all types of disabilities on the basis of functional need.	<i>Served to individuals with a mental impairment.</i>
2. <input checked="" type="checkbox"/>	Program serves people of all ages.	
3. <input checked="" type="checkbox"/>	PAS include, but are not limited to: (see definitions at end for complete description of each service listed) <ul style="list-style-type: none"> • personal services • household services • child & infant care assistance • life skills support services • communication services • security-enhancing services • mobility services both in & outside of home • service coordination • assistive technology • emergency services 	<i>Day Habilitation Services</i> <i>Supported Employment</i> <i>Respite Services</i> <i>Home Order Services</i> <i>Residential Training and Supervision</i>

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
4. ____	No medical supervision is required.	<i>Supervision is provided by Provider if necessary except for Personal Care which is provided by RN</i>
5. ____	Both domestic and personal care services (including catheterization & tracheostomy management) are available from the same program.	
6. ____	The program does not restrict individual providers from administering medications or injections or from carrying out catheter or tracheostomy management.	<i>Medication administration is limited to skilled nursing assistance with administration of oral medication is permitted by other disciplines</i>
7. ____	There are no maximum limits on hours of utilization (mark with a circle if there is a maximum but it is greater than 20 hours per week).	<i>There are limitations on some services (see manual)</i>
8. <input checked="" type="checkbox"/>	Natural/informal supports are not supplanted or discouraged by PAS but are encouraged and supplemented by PAS so that natural supports are available to PAS user in the same way they are available to all citizens.	

**Personal Assistance Services
PAS
Desirable Design Criteria checklist**

#	Desired design criteria	Current actual design criteria of program being rated
9. _____ _____ _____ ✓ _____ ✓ _____	<p>User* has a choice of type of service provider, hours of availability & location of support:</p> <p>The following choices are available:</p> <ul style="list-style-type: none"> • person receives cash or voucher to hire self-employed individual providers including family members, employed & supervised by the user. • person has control of hiring, firing, training, supervising individual provider but agency is actual employee (fiscal agent) • agency providers employed and supervised by a private or public agency. • available on 24 hr./day, 7 day/week basis • available on visiting, live-in, respite, emergency, and/or short term basis. • available in a variety of settings & for a variety activities including but not limited to home, work, school, recreation, leisure, travel & politics. 	<p><i>Residential Training & Supervision</i></p>
10. _____	There is no income eligibility (mark with a circle if income is a criterion but maximum allowable income is at least 300% of the poverty level).	<p><i>Services are provided for SS / recipients.</i></p>
11. _____	For people with incomes over 300% of the poverty level PAS are offered on a cost sharing basis. tives to PAS.	<p><i>Expected to be offered in the future waived</i></p>

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
12.____	No user is required to pay more than 2% of net income, after disability related expenses are deducted, on PAS.	
13.____	No resource test is applied to non-income assets of eligible people.	
14.____	Payments to users are not treated as disposable taxable incomes & do not make users ineligible for other statutory benefits & services.	
15.____	There are no employment disincentives to PAS.	
16.____	User can hire & fire the personal assistant.	
17.____	User can receive a direct cash grant & pay the personal assistant.	
18.____	User can determine the training requirements for personal assistants; none other is required.	

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
19. ____	Recruitment & training of personal assistants is available as needed.	
20. <input checked="" type="checkbox"/>	User can participate in the assessment & planning process that determines the type of service & number of hours allocated to user.	
21. ____	Funding for PAS comes from a stable, long term source.	
22. ____	Personal assistants receive reasonable remuneration & basic benefits.	
23. ____	Program has a process to protect assistants including a grievance mechanism.	/

Adapted from CCD, 1991; WID, 1987 & 1991; Ratrzka, 1986; Kapp, 1990)

* NOTE: Anywhere the work "user" is found, this applies to the person actually receiving/using a PAS and/or the person's legal representative or guardian.

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

Name (type) of program being rated: DRS Personal Assistance Program
 Administered by: Lee Ann Henderson
 Provided by: DRS

Date: June 15, 1992

Check each statement that is true of the program you are rating. For each statement that is not checked (does NOT describe an accurate feature of the program being rated), please write in what is accurate about the program being rated in relationship to the statement.

#	Desired design criteria	Current actual design criteria of program being rated
1. <input type="checkbox"/>	Program serves people with all types of disabilities on the basis of functional need.	Mobility Impaired people only. Not available for people who are deaf or blind.
2. <input type="checkbox"/>	Program serves people of all ages.	18 years + older.
3. <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	PAS include, but are not limited to: (see definitions at end for complete description of each service listed) • personal services • household services • child & infant care assistance • life skills support services • communication services • security-enhancing services • mobility services both in & outside of home • service coordination • assistive technology • emergency services	

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

Desired design criteria Current actual design criteria of program being rated

#	Desired design criteria	Current actual design criteria of program being rated
4. <input checked="" type="checkbox"/>	No medical supervision is required.	
5. <input checked="" type="checkbox"/>	Both domestic and personal care services (including catheterization & tracheostomy management) are available from the same program.	Yes to catheterization No to tracheostomy tracheostomy - limited basis
6. <input checked="" type="checkbox"/>	The program does not restrict individual providers from administering medications or injections or from carrying out catheter or tracheostomy management.	..
7. <input checked="" type="checkbox"/>	There are no maximum limits on hours of utilization (mark with a circle if there is a maximum but it is greater than 20 hours per week).	
8. <input checked="" type="checkbox"/>	Natural/informal supports are not supplanted or discouraged by PAS but are encouraged and supplemented by PAS so that natural supports are available to PAS user in the same way they are available to all citizens.	

**Personal Assistance Services
PAS
Desirable Design Criteria checklist**

#	Desired design criteria	Current actual design criteria of program being rated
9. <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<p>User* has a choice of type of service provider, hours of availability & location of support:</p> <p>The following choices are available:</p> <ul style="list-style-type: none"> • person receives cash or voucher to hire self-employed individual providers including family members, employed & supervised by the user. • person has control of hiring, firing, training, supervising individual provider but agency is actual employee (fiscal agent)* • agency providers employed and supervised by a private or public agency. • available on 24 hr./day, 7 day/week basis • available on visiting, live-in, respite, emergency, and/or short term basis. • available in a variety of settings & for a variety of activities including but not limited to home, work, school, recreation, leisure, travel & politics. 	<p>→ No to family members</p> <p>→ will be offered as of July 1992</p>
10. <input type="checkbox"/>	There is no income eligibility (mark with a circle if income is a criterion but maximum allowable income is at least 300% of the poverty level).	
11. <input type="checkbox"/>	For people with incomes over 300% of the poverty level PAS are offered on a cost sharing basis.	No, this program limited to 50% w/ income up to 125% of poverty level.

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Division of Rehabilitation Services

The Independent Living Program is part of the Division of Rehabilitation Services (DRS) of the Department of Human Resources (DHR). There are three distinct parts to the program: (1) A community based Independent Living component; (2) the Atlanta Center for Independent Living (ACIL); and (3) a six week Independent Living component at Roosevelt Warm Springs Institute of Rehabilitation.

Independent Living Program

- Lee Ann Pendergrass is the State Coordinator for the Independent Living Program. There are six Independent Living Counselors located in six districts around the state: Gainesville, Augusta, Savannah, Columbus, Macon, & Albany.

- Direct services offered or coordinated for individuals, include:

—Case intake and management	—Advocacy	—Environmental home surveys
—Information and referral	—Individual & family counseling	—Public assistance benefits
—Technical assistance	—Peer counseling	—Skills training

- In 1991, Roosevelt Warm Springs Institute on Rehabilitation provided the Independent Living Program with \$343,400.00 to spend over a 2-3 year period for personal assistance services (PAS). This money is part of the Institute's Indigent Care Trust Fund's allotment for primary care. These funds are to be used for people with severe physical disabilities who are seen to have the ability to live independently in the community. The money is divided among the counselors in their areas based on need.

- Eligibility criteria:

- Be 18 years old or older
- Be a resident of Georgia
- Have a severe disability
- Be eligible for Medicaid
- Be able to instruct and supervise attendants
- Be a graduate of the Roosevelt Warm Springs Institute training program on independent living
- Be willing to work with the Independent Living Coordinator

- Priority will be given to individuals who are currently in nursing homes or institutions or in immediate danger of going into a facility unless they receive personal assistance.
- People selected to use these funds can go through a home health agency or hire independent assistants. Up to \$7.00/hour can be paid for personal assistance. Healthmaster Home Health Care of Georgia has agreed to provide attendants at this rate and is one option a person can select.
- As of mid-March there were six people being supported on the Independent Living Program with a total of ten people expected by the end of April.

homemaker services.

- **Personal care:** Personal care including grooming, bathing, assistance with clothing, toileting, assistance with medications, meal preparation, accompanying to obtain medical treatment. May be provided by a family member (parents of minors and spouses excluded) under some circumstances. Justification for paying a family member must be provided. Family members providing care must meet same standards as unrelated providers.
- **Environmental modifications:** Excludes adaptations or improvements to the home which are not of direct medical or remedial benefit to the person. Does not include basic construction costs of new buildings. Total dollar amount limited to \$8000/person/residence.
- **Skilled nursing:** Performance of health care procedures, monitoring a person's health care condition and training family members and other Independent Care providers in dietary practices, sanitation, health monitoring and maintenance, and appropriate use of medical services & procedures. Must be provided by a registered professional nurse licensed to practice in the state of Georgia.
- **Transportation:** Non-medical & unavailable under state plan. May be provided by public carriers or by Medicaid approved.
- **Specialized medical equipment & supplies** including devices, controls, or appliances which enable a person to increase ability to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live.
- **Personal emergency response systems:** Provider shall have a seven (7) day a week, twenty-four (24) hour a day system designed for individuals with disabilities living in the community.
- **Companion services:** Non-medical care, socialization.
- **Occupational Therapy**
- **Reimbursement:** DMA reimburses Independent Care providers for services rendered at rates established by DMA. There is no overall dollar cap per person, but there are certain limitations on (1) environmental modification; (2) vehicle adaptation; (3) specialized medical equipment and supplies; and (4) personal emergency response services.
 - Each person will receive an individualized array of services tailored to his or her need. Some people will receive intense services, others less intensive. It depends on the person. The limitation on expenditures will not be determined person by person, but by an aggregate averaging of total expenditures. The average of all costs for people served by Independent Care must not exceed the maximum allocated funds per year in the aggregate. DMA will monitor service costs through each Individual Plan of Care to make sure services can be provided within allowed resources.
- **Providers of Independent Care Services must:**
 - Be currently licensed or certified by the appropriate municipality OR have experience working with the specific target group. Must have permits has required. Copy of license, certification, permit, or resume must be submitted to Provider Enrollment Unit of DMA.
 - Maintain adequate records in accordance with Independent Care Services requirements & professional standards & practice.
 - Agree to periodic on-site reviews and audits.
 - Bill only for those services authorized by DMA and provided to authorized recipients.
 - Not bill DMA more for people on Medicaid than for private pay patients and be able to prove in writing for 3 years.
 - Maintain staff to adequately and appropriately provide the required services

- **People who are NOT eligible**

- (1) **People who are inpatients and residents of a nursing home (Skilled Care, Intermediate Care, or Intermediate Care for the Mentally Retarded.**
- (2) **People receiving support under any other state of Georgia waived services**
- (3) **People for whom the cost of waived services will exceed the cost of the same level of care in an institution.**

Independent Care Waiver

- **The Independent Care Waiver is Georgia's newest waived services program approved for three years with start-up in May, 1992. This waiver was submitted by the Department of Medical Assistance (DMA) and will be directly operated by the DMA's Division of Community Services. Its purpose is to provide in-home and community supports to adults (currently living in or at risk of being admitted to a nursing facility, hospital or hospital nursing facility) who have physical impairments which require assistance from another person in order to carry out everyday tasks and who also may be dependent on ventilators or tracheostomies for breathing, but who are stable medically. Currently, people in this situation stay at home with virtually no support to the person, family, or allies, or they remain in inpatient hospitals such as Grady or Vencor, or Shepherd Spinal Center (at costs approaching \$800/day) for years at a time. Even nursing homes in Georgia have been unwilling to take people on ventilators using the current reimbursement rates. This has resulted in an unknown number of people being placed in out-of-state nursing homes.**

- **Eligibility criteria**

- (1) **The person is an adult (over 21 years of age & older) who has significant physical disabilities but whose medical condition is stable.**
- (2) **The person's disability (physical impairment) limits her/his functioning to the degree that the person requires assistance from another person to do everyday tasks.**
- (3) **The person is medically stable but currently resides in a nursing facility, hospital, or a hospital nursing facility or is at risk of being placed in one because of lack of community-based supports (priority for those people on ventilators who have been moved out of state).**
- (4) **The person currently receives the level of care provided in a hospital or nursing home under the Medicaid State Plan, and for whom home and community-based services are determined to be an appropriate alternative.**
- (5) **The person is eligible for Medicaid, Medical Assistance Only (MAO) or would be eligible for Medicaid if in an institution and would require placement in an institution in the absence of community support systems.**
- (6) **The person lives in or wants to return to Atlanta, Albany, Columbus, Savannah, or Augusta areas. (This may be expanded when renewed.)**
- (7) **The person cannot receive services under Independent Care and any other waived service at the same time.**

- **These supports are available under this waiver:**

- **Case management: Focal point for person's service planning and delivery. May be individual practitioners or employed by public or private agencies.**
- **Homemaker: General household activities provided by trained homemaker when person responsible for these activities is temporarily absent or unable to do them. Spouses may NOT be paid to provide**

– Added services include Case management, environmental modifications, vehicle adaptations and specialized medical equipment.

– An increase in the number of people to be served on the waiver. The waiver projects 350 people/year to be served (200 people/year from institutions and 150 people from the community). This would be a total of 2109 people between the years of 1989-1987.

• The following home and community-based services are included in the waiver:

- Service Coordination (formerly case management)
- Respite Care
- Habilitation (residential & day habilitation and supported employment services)
- Environmental modifications
- Specialized medical equipment and supplies, including assistive technology, adaptive equipment, vehicle adaptations, and specialized supplies
- Personal Emergency Response Systems
- Home health care services (extended state plan services permitting an additional 290 visits/year))
- Personal Support Services: a variety of services based on the specific needs of the person; can range from 1-24 hours per day; cannot make payments directly or indirectly to family members; total cost of 24 hour personal support cannot be more than the 24 hour cost of residential training and supervision.

• Eligibility requirements

- (1) Person must be adult (over 21 years of age) and have a documented primary diagnosis of mental retardation OR for people who are currently residing in an institution, the person has other conditions closely related to mental retardation requiring services similar to a person with mental retardation.

AND meet either #2 or #3

- (2) The person is eligible for Medicaid or will become eligible for home and community based services with a special income level at 300% of SSI (excludes person who is eligible for Medical Assistance Only (MAO)).
- (3) The person is deemed income eligible for Medicaid (is considered a "Family of One."

AND meet either #4, #5, or #6

- (4) The person is currently in an ICF/MR program which is reimbursable under the State Plan and home and community-based services are an appropriate alternative.
- (5) The person currently receives non-institutional services reimbursable under the State Plan as an alternative to institutional care, and home and community-based services are the most cost effective way to continue to prevent institutionalization.
- (6) The Georgia Medical Care Foundation (GMCF) has determined the person to need the level of care provided in an ICF/MR and home and community-based services are determined to be an appropriate alternative.

(A person must meet criteria 1, and either 2 or 3, and either 4, 5, or 6 and the person and/or the person's legal guardian must choose home and community-based services instead of institutional services.)

which is reimbursed in half hour increments.

- (2) **Homemaker Aide Services:** Assistance with meal preparation, hygiene and nutrition; light house-keeping, shopping and other support services.
 - (3) **Emergency Response Services:** In-home electronic support system providing two-way communication between isolated persons and a medical control center.
 - (4) **Respite Care:** In-home respite care provided by a aide for up to five hours a day; out-of-home overnight respite care in an approved facility with 24-hour supervision; out-of home day respite care in an approved facility for up to five hours per day.
 - (5) **Adult Day Rehabilitation:** Daytime care and supervision in an adult day center; nursing and medical social services; planned therapeutic activities; P.T., O.T, and speech therapy; meals, including prescribed diets.
 - (6) **Alternative Living Services:** alternative residence for a person unable to remain independent in his or her own home; meals, personal care and supervision.
- Each of the 18 Lead Agency Geographic Service Areas is assigned a number of slots for the CCSP program. At present the program is full and is only accepting new people when someone leaves the program. There are waiting lists for CCSP all across the state. In at least one of the Lead Agency Geographic Service Areas there are 189 people on the waiting list. There are currently over 8000 people being served in the CCSP program.

Model Waiver Services

- This is a program for children and young people ages birth-21 years of age. It provides private duty nursing for children who are ventilator or oxygen dependent and have other medical complications that require skilled nursing supervision.
 - There are no personal care services under this waiver. All services are skilled nursing services.
 - The maximum number of children who can be served under this waiver is 100. There are currently 60 children being supported by this waiver.
 - This program originally had age 10 as its upper age limit. It has been raised twice: once from ten to twelve; most recently from twelve to twenty-one.

Home and Community-Based Services Waiver for People with Mental Retardation

- Georgia has submitted a request for a five year renewal of the Home and Community-Based Services Waiver for People with Mental Retardation with a number of enhancements from the original waiver. This waiver will be for people with mental retardation and developmental disabilities regardless of age. This is a major effort to minimize the use of institutions and increase the possibility that people with high levels of need for support can stay at home or live in other community alternatives. As of June 8, 1992, the state had not received approval of this renewal request.
- Some of the changes from the original waiver are:
 - The renewal focuses on people who will require the most intense supports and who are most at risk of being placed out of home or of remaining in an ICF/MR program.
 - Changes in services offered: A new service category called Personal Support has been added.

Community Care Services Program

- The Community Care Services Program (CCSP) is a Medicaid waiver program reimbursed under the Georgia Medicaid Waiver for Community and In-home Services. It is administered through Offices of Aging. This program provides people with community-based services as an alternative to institutionalization.
- To be eligible for Community Care Services a person must meet the following criteria:
 - (1) The person must have a functional impairment (physical or mental limitation which restricts the person's ability to perform normal activities of daily living and which impedes the person's capacity to live independently).
 - (2) The person must be Medicaid eligible or potentially Medicaid eligible.
 - Be on SSI (individual income below \$422 per month; couple income below \$633 per month);
 - Be on Medical Assistance Only [MAO] (person is eligible with individual income between \$422-\$1266 per month; couple income between \$633-\$2532 per month);
 - Individuals who get SSI or MAO are allowed assets of below \$2000 /individual or \$3000/couple;
 - For 180-day Potential MAO Eligibility the same income limits apply as above, but the person has assets above the maximum allowed which would be exhausted within 180 days of admission to a nursing home.
 - The person must pay for services until their resources are spent down to the level required by Medicaid.
 - A person who is MAO eligible may divert up to \$1,718 per month of income to a husband or wife who is not institutionalized. If person has spouse who is not in an institution or receiving CCSP services, that husband's or wife's assets have to be considered in determining eligibility. The total combined assets of the person plus spouse must be \$70,000.00 or less. All assets above \$2000.00 belonging to the person applying for Medicaid must be transferred to the husband or wife within one year from the initiation of Medicaid. People who are on MAO or 180 day MAO potential may have to cost share. The Social Security Administration is responsible for taking SSI applications; local Departments of Family and Children Services take applications for MAO.
 - (3) The person must be pre-certified for intermediate or skilled nursing home care.
 - (4) The person's health needs must be adequately met in the community within established cost limits set for CCSP (a cap of \$750.00/mo. or \$8400.00/year).
 - (5) Person must express a preference for community-based services over nursing home services.
 - (6) The person does not have to be homebound.
 - (7) There is no age limit although priority may be given to people who are 60 years old or older.
- The Community Care Services Program offers six services: (The rules and regulations surrounding these services are so complex that there is a separate manual for each one. As one person expressed it, "This is a very complicated program, layered in bureaucracy. It's very difficult for a person to get on the program because there is a long waiting list. But if you can get a slot it's wonderful. You don't have to be homebound. You can live a more independent and socialized existence than with Home Health Services or in a nursing home.")
 - (1) Home-delivered services: skilled nursing services; P.T., O.T., and speech therapy; medical social services and home health aide assistance; personal care and help with meals; and medically related transportation. All of these services are reimbursed on a per visit basis except for personal care

Home Health Services

- Home Health Services are part of the state Medicaid plan. Home Health Agencies must be licensed by the Standards and Licensure Unit of the Department of Human Resources and certified to provide services under Medicare. All home health agencies started after 6/30/79 have to be approved by and have a certificate of need from the State Health Planning Agency.
- Services available include:
 - (1) Skilled nursing
 - (2) Home health aides services
 - (3) Physical therapy, speech therapy, and occupational therapy
- In order to receive Home Health Services, the following criteria must be met:
 - (1) There is a reasonable expectation that the person's medical and nursing needs can be adequately met by the agency in the person's home.
 - (2) There must be a written Plan of Treatment that is established and periodically reviewed by a licensed physician.
 - (3) There must be continued supervision of the person by a physician at least every sixty days or every two months.
 - (4) There must be an absence or inability of significant others to provide the services.
 - (5) The person must be home-bound.
 - (6) The person must be Medicaid eligible.
 - (7) A Home Health Agency cannot provide Home Health Services and services under the Community Care Services Program to the same person at one time.
- New limitations:
 - (1) Will only pay for 5 medications (down from 6)
 - (2) Limit of 75 visits per year (down from 100)

Waivered Services

Prior to 1981 states could only use Medicaid funds for Intermediate Care Facilities for the Mentally Retarded (ICF/MR) which meant state hospitals and some community group homes. The Title XIX Home and Community Based Services Waiver process was authorized by the Omnibus Budget Reconciliation Act (OBRA) of 1981. This allows states to apply for a waiver of traditional Medicaid requirements so that people with mental retardation or a related condition can use funds in home or community based services. Many other states began using the waived services program when it became available. Georgia did not get into waived services for people with developmental disabilities until 1988.

States must apply to the federal government and meet certain requirements to be approved. The application process is cumbersome requiring complicated financial formulae to prove cost effectiveness. Waivers are granted for a specified time period. First time waivers applications are approved for three years. A state must then reapply. Reapplications can request approval for up to five years.

Gary Redding of DMA would like to see the services that are now waived become optional services under Georgia's State Medicaid Plan. This would eliminate the time consuming, complicated and cumbersome application and renewal process.

Appendix C

Selected Programs That Provide Community Support to Georgians with Severe Disabilities

Several programs in Georgia provide some form of community support services to people with severe disabilities. Eligibility criteria, cost sharing requirements, types of services covered plus amount, and duration of services varies from program to program. The following outlines the basic components of each.

Medicaid

Medicaid is a joint federal and state health care program designed to provide medical assistance to people who meet certain income & asset criteria. Individuals are eligible if they receive Supplemental Security Income (SSI) or Aid to Families with Dependent Children (AFDC), or if their income is no more than \$1221.00/mo. (\$2442.00/mo. for a couple) and assets are no more than \$2000.00/ individual (\$3000.00 for a couple). The Georgia Department of Medical Assistance (DMA) is the state agency responsible for operating Medicaid programs.

Georgia Medicaid Services

Ambulance Services	In and Outpatient Services	Nurse Practitioner Services
Ambulatory Surgical/Birthing Center Services	Independent Care Walver	Orthotic and Prosthetic Services
Community Care Services	Intermediate Care Facility Services	Perinatal Case Mgmt. Services
Dental Services	Intermediate Care for the Mentally Retarded Facility Services	Physician Services
Dialysis Services	Laboratory and Radiological Services	Podiatric Services
Durable Medical Equipment Services	Mental Health Case Mgmt. Services	Pregnancy-Related Services
Early & Periodic Screening, Diagnosis & Treatment Services	Mental Health Clinic Services	Prescribed Drugs
Family Planning Services	Mental Retardation Walver Services	Psychological Services
Home Health Services	Model Walver Services	Rural Health Clinic Services
Hospice Services	Non-Emergency Transportation	Skilled Nursing Facilities
	Nurse Midwifery Services	Swing Bed Services
		Vision Care Services

source: DMA 1991 Annual Report

Those services in bold print are those of primary interest to this project and are briefly described below. One of these, Home Health Services, is a regular state plan service, and the four others are waived services.

**Personal Assistance Services
PAS
Desirable Criteria Checklist**

Name (type) of program being rated: Georgia Options

Date: _____

#	Desired criteria	Current actual criteria of program being rated
19. <input checked="" type="checkbox"/>	Recruitment & training of personal assistants is available as needed.	Agency will be ultimately responsible with individuals & families playing as much of a role as they can.
20. <input checked="" type="checkbox"/>	User can participate in the assessment & planning process that determines the type of service & number of hours allocated to user.	Consumers will always be involved in planning.
21. <input type="checkbox"/>	Funding for PAS comes from a stable, long term source.	Medicaid Waiver We can't risk having people on soft money.
22. <input type="checkbox"/>	Personal assistants receive reasonable remuneration & basic benefits.	Salaries & benefits are not definite at this time
23. <input type="checkbox"/>	Program has a process to protect assistants including a grievance mechanism.	Will have grievance process with personnel committee & board as well as the director.

* NOTE: Anywhere the work "user" is found, this applies to the person actually receiving/using a PAS and/or the person's legal representative or guardian.

Adapted from CCD, 1991; WID, 1987 & 1991; Ratrzka, 1986

$$+i$$

Date: _____

#	Desired criteria	Current actual criteria of program being rated
12.____	No user is required to pay more than 2% of net income, after disability related expenses are deducted, on PAS.	People's income (-\$60/mo) will go to their room & board. Medicaid Waiver dollars will pay for Personal Support.
13.____	No resource test is applied to non-income assets of eligible people.	None Known
14.____	Payments to users are not treated as disposable taxable incomes & do not make users ineligible for other statutory benefits & services.	Payments aren't made to users. (Not sure what problems it would create with benefits)
15.____	There are no employment disincentives to PAS.	None Known
16.____	User can hire & fire the personal assistant.	Would collaborate with agency to make these decisions.
17.____	User can receive a direct cash grant & pay the personal assistant.	Not set up this way
18.____	User can determine the training requirements for personal assistants; none other is required.	Agency will have some requirements (DHE and standards) Training specific to the individual will also be done.

**Personal Assistance Services
PAS
Desirable Criteria checklist**

Name (type) of program being rated: Georgia Options

Date: _____

#	Desired criteria	Current actual criteria of program being rated
9. _____ _____ ✓_____ _____ ✓_____ ✓_____ ✓_____	<p>User* has a choice of type of service provider, hours of availability & location of support: The following choices are available:</p> <ul style="list-style-type: none"> • self-employed individual providers including family members, employed & supervised by the user. • person has control of hiring, firing, training, supervising individual provider but agency is actual employee(employer) • agency providers employed and supervised by a private or public agency. • available on 24 hr./day, 7 day/week basis • available on visiting, live-in, respite, emergency, and/or short term basis. • available in a variety of settings including but not limited to home, work, school, recreation, leisure, & travel. 	<p>We want families and people with disabilities to have input in hiring, firing, & training. The agency will do the recruiting & have interested people participate in hiring. We want staff to have the chance to get to know people before they move into their new homes.</p> <p>Don't think family members (parents, spouse) can be paid to provide care.</p> <p>All of our 1st consumers need 24 coverage but short term basis could be done, too, with other people</p>
10. _____	There is no income eligibility (mark with a circle if income is a criterion but maximum allowable income is at least 300% of the poverty level).	People have to be eligible for medicaid & SSI. I don't think we get the institutional deeming amount.
11. _____	For people with incomes over 300% of the poverty level PAS are offered on a cost sharing basis.	Wouldn't be possible if ineligible for Medicaid.

**Personal Assistance Services
PAS
Desirable Criteria Checklist**

Name (type) of program being rated: GEORGIA OPTIONS

Date: _____

#	Desired criteria	Current actual criteria of program being rated
4. ____	No medical supervision is required.	The 5 people don't need medical supervision
5. ____	Both domestic and personal care services (including catheterization & tracheostomy management) are available from the same program.	Would try to provide both, but don't have experience yet.
6. ____	The program does not restrict individual providers from administering medications or injections or from carrying out catheter or tracheostomy management.	No - will be some record keeping required around administering meds.
7. ____	There are no maximum limits on hours of utilization (mark with a circle if there is a maximum but it is greater than 20 hours per week).	Can provide 24 hr/day support
8. ____	Natural/informal supports are not supplanted or discouraged by PAS but are encouraged and supplemented by PAS so that natural supports are available to PAS user in the same way they are available to all citizens.	Families & friends are encouraged to be involved as much as they want to be... They are not expected to provide people's basic care... Georgia Options is responsible for that.

Personal Assistance Services PAS

Desirable Criteria Checklist

Name (type) of program being rated: GEORGIA OPTIONS

Date: 6/20/92

Check each statement that is true of the program you are rating. For each statement that is not checked (does NOT describe an accurate feature of the program being rated), please write in what is accurate about the program being rated in relationship to the statement.

#	Desired criteria	Current actual criteria of program being rated
1. <input type="checkbox"/>	Program serves people with all types of disabilities on the basis of functional need. <i>I think new waiver lets people w/developmental disabilities be served if they have ever been in an ICF-MR facility</i>	With Medicaid Waiver funding, people served must have mental retardation - We had wanted to serve people with M.H. problems too but no funding. People being served also have cerebral palsy, autism, Down Syndrome, vision & hearing problems.
2. <input type="checkbox"/>	Program serves people of all ages.	Would consider all ages 1st five people to be served are all adults
3. <input type="checkbox"/>	PAS include, but are not limited to: (see definitions at end for complete description of each service listed) <ul style="list-style-type: none"> <input checked="" type="checkbox"/> • personal services <input checked="" type="checkbox"/> • household services <input type="checkbox"/> • child & infant care assistance <input checked="" type="checkbox"/> • life skills support services <input checked="" type="checkbox"/> • communication services <input type="checkbox"/> • security-enhancing services <input checked="" type="checkbox"/> • mobility services both in & outside of home <input checked="" type="checkbox"/> • service coordination <input checked="" type="checkbox"/> • assistive technology <input checked="" type="checkbox"/> • emergency services 	The agency director will coordinate services, arrange emergency backup, and assisting with recruitment & training of personal assistants. Live-in roommates & extra help as needed will provide personal services, household services, life skills support, communication, & mobility Would consider other 2 services but need hasn't been expressed.

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
19. <input checked="" type="checkbox"/>	Recruitment & training of personal assistants is available as needed.	
20. <input checked="" type="checkbox"/>	User can participate in the assessment & planning process that determines the type of service & number of hours allocated to user.	
21. <input type="checkbox"/>	Funding for PAS comes from a stable, long term source.	No, indigent care funds from Wabem Spring Rehab Institute.
22. <input type="checkbox"/>	Personal assistants receive reasonable remuneration & basic benefits. ??	As of July - 7.00 per hr. plus unemployment. No vac. or sick time.
23. <input type="checkbox"/>	Program has a process to protect assistants including a grievance mechanism.	No, good idea though!!

*NOTE: Anywhere the work "user" is found, this applies to the person actually receiving/using a PAS and/or the person's legal representative or guardian.

Adapted from CCD, 1991; WID, 1987 & 1991; Ratrzka, 1986; Kapp, 1990)

**Personal Assistance Services
PAS
Desirable Design Criteria Checklist**

#	Desired design criteria	Current actual design criteria of program being rated
12. <input type="checkbox"/>	No user is required to pay more than 2% of net income, after disability related expenses are deducted, on PAS.	
13. <input checked="" type="checkbox"/>	No resource test is applied to non-income assets of eligible people.	
14. <input type="checkbox"/>	Payments to users are not treated as disposable taxable incomes & do not make users ineligible for other statutory benefits & services.	
15. <input checked="" type="checkbox"/>	There are no employment disincentives to PAS.	
16. <input checked="" type="checkbox"/>	User can hire & fire the personal assistant.	OR use agency. Their choice.
17. <input checked="" type="checkbox"/>	User can receive a direct cash grant & pay the personal assistant.	
18. <input checked="" type="checkbox"/>	User can determine the training requirements for personal assistants; none other is required.	