

Aging Caregivers of Individuals with Developmental Disabilities in the State of Georgia



**University Affiliated Program
for Persons with Developmental Disabilities**

College of Family and Consumer Sciences
University of Georgia

Highlights of the CONSUMER DISCOVERY PROJECT

AGING CAREGIVERS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES IN THE STATE OF GEORGIA

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NOTE: Although we endorse the use of People First language, all caregivers comments quoted in this document are presented in the words actually used by the caregivers. We believe it would be inappropriate to edit or rephrase their comments.

THE CONSUMER DISCOVERY PROCESS

BACKGROUND & PURPOSE

We grow up with the dream that we will get married, have children and at some point in time our children will leave home and start a family of their own. For a growing number of older parents, this is not reality, some of their children do not leave home. These parents continue to provide ongoing care to their adult daughters, sons, and other family members with developmental disabilities.

The Governor's Council on Developmental Disabilities for Georgia set one of their goals to be the strengthening of supports available to these aging caregivers. The Governor's Council delineated a number of activities designed to help meet this goal. One was to develop a research and planning effort that was targeted to aging caregivers of individuals with developmental disabilities and their families.

Once you get used to being alone and not going, I've never been a gadabout, to begin with, and, not that I love to stay home and do housework either, I'm not a housekeeper either. But, well, what I'm trying to say is, I, you know, I don't have to have a lot of people around me all the time. I love to have company and I love to communicate, but it's not necessary for me to have someone there, you know, on a regular basis all the time, and I know lots of people it is. They have to see somebody outside the family every day.

METHODS USED

Teams composed of two Consumer

Discovery Staff members interviewed 36 aging

caregivers of individuals with developmental

disabilities across the State of Georgia. The

interviews were audiotaped and where

permissible videotaped as well. Individuals were

recruited through both formal service providers

(Department of Mental Health, Mental

Retardation, and Substance Abuse; Vocational

Rehabilitation; Council on Aging) and informal

service providers (churches, hair stylists and

others).

My greatest dream and greatest hope is that she would be cared for and I do not know--for instance, I don't know, if we know whether it would be in this home and I lean towards thinking that that might be it. But the future--20 years or 30 years from now is probably the greatest, if you want to call it a worry or concern, . . . , that we have at this moment

CHARACTERISTICS AND SERVICE NEEDS OF AGING CAREGIVERS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

DEMOGRAPHICS

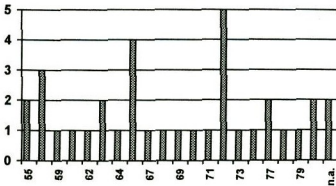
The individuals that we spoke with ranged

in age from 55 to 86. The mean age was 65

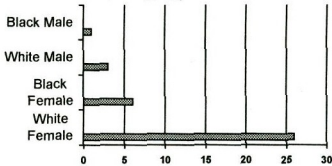
years. Two people did not tell us their age nor

their year of birth.

**Ages of Caregivers
(n=36)**



**Gender and Ethnicity
(n=36)**



**Marital Status of Caregivers
(n=36)**



Int: What is your current marital status?

C: I'm a widow.

Int: Okay. How long were you married?

C: Oh geezers, 40 something years, we married in 1945 and my husband died in 89.

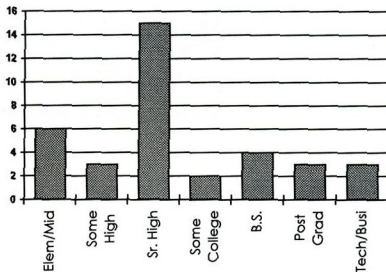
Most of the caregivers (83%) were the mothers of the individual with a disability.

The majority (75%) of caregivers had at least a high school education. One-third had some post-secondary education.

Int: So did you go all the way through high school?

C: No, no, I don't even think I got, I don't think I finished the eighth grade. But it wasn't because I didn't want to. It was because, you know how, it was the Depression.

**Level of Education
(n=36)**



Only three of the aging caregivers had never worked outside of the home. Nearly a third of the people that we spoke with held professional or para-professional positions at their last job.

A few of the people (n=5) that we spoke with were providing care to more than one person with a developmental disability.

TYPE OF DISABILITY	# OF INDIVIDUALS
Down Syndrome/Mental Retardation	21
Cerebral Palsy	9
Autism	4
Sensory Impairments	4
Seizures/Seizure Disorder	4
Physical Disabilities	3
Traumatic Brain Injury	2
Learning Disability	2

Financial Issues

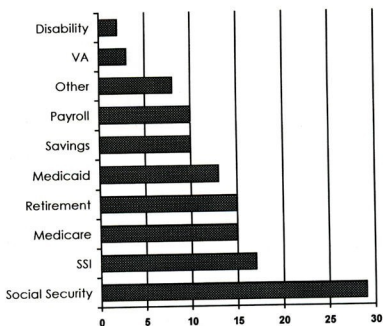
Most (81%) of the aging caregivers were receiving Social Security. The majority (72%) of caregivers that we spoke with were receiving income from 2 to 5 sources.

You know, it could have been a lot worse had we not had the money to take care of us. To buy the medication, to do what we've done. I can't imagine having a child like Mark and not having the means of this kind of support.

Int: Ok. How much stress do you and your family experience because of money?

C: We don't get stressed because we know it's got to be paid, the bill's got to be paid. We put in all the money and we pay them. And if we have some money, it's alright, and if we don't, we know the bill's paid, cause we got to live to next week. That's the way we take care of it. It's our responsibility.

Sources of Income
(n=36)



In general, the majority (67%) of the aging caregivers indicated that their current financial situation did not cause them stress. However, twelve of the people that we spoke with were experiencing some level of stress due to their financial situation. Fewer people felt as secure about their financial ability to cover their medical and health care expenses.

Periodically, we all want to splurge and enjoy the little extras in life. However, 28% of the aging caregivers that we spoke with said that they could never afford them. Thirty-one percent said that they could afford them occasionally, but not very often.

The majority of people were positive about their financial ability to meet their future needs. However, one fourth of the aging caregivers did not know whether or not they could afford the future. Nearly as many knew that they could not.

C: Yep its tight, but we make it with the Lords help.

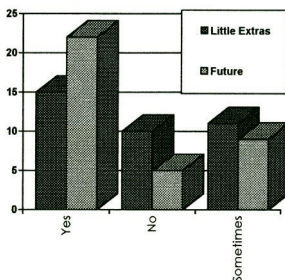
Int: Ok, do you have enough usually to buy the little extras that you want sometimes?

C: Sometimes, sometimes we don't, but not all the time

Int: Do you feel that for your future needs you'll have enough money to cover what you need?

C: Unless medicine goes up(laugh). I'm still paying on their hospital bill.

**Ability to Afford
(n=36)**



My husband has to do all the vacuuming, he has to do all the heavy lifting, I've had a radical hysterectomy, a recticell, bladder tack, and then surgery all in here and on this shoulder and arm so I'm limited but, I can walk, I can do, I can cook

Health Issues

Well, I have a lot of breathing problems. When our house burned in '92, I suffered smoke inhalation and was hospitalized. And that's why I'm no longer able to work, because of lung damage. And arthritis.

Of the 36 aging caregivers the majority (64%) felt as if they were in good or excellent

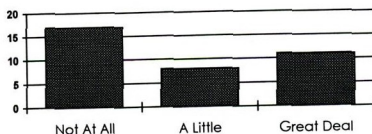
health. Four felt they were in poor health.

Although for the most part these caregivers perceived themselves to be in good health,

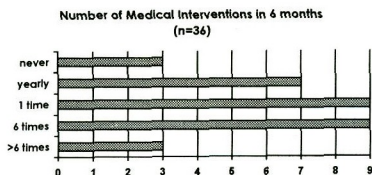
there were those who were dealing with complicated health issues of their own.

However, for the majority of the aging caregivers that we spoke with their health troubles stood in the way of things that they wanted to do either a great deal (31%) or a little (22%).

Impact of Health Troubles on Daily Activities
(n=36)



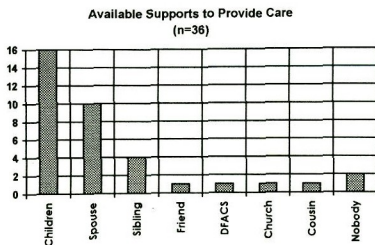
One third of the people that we spoke with saw the doctor at least once a month in the six months prior to our conversation. Only three had been admitted to the hospital in the six month period prior to our conversation.



Ah, well I have not seen a doctor except for I went for my physical in January in the hospital. We just have a little physical. But I have not been to my doctor. Oh wait a minute! (laugh) I don't know how I could have forgot! I had gall bladder surgery, (laugh) what am I saying! I really don't even remember when it was.

Overwhelmingly, the people that we spoke with (86%) had supports in place to assist them in providing care for their son or daughter on a short term basis should they take ill.

Like if I be in the hospital, my children would help me.



Activities of Daily Living

There's been times when I could have used that assistance (laughs) but, no, I've pretty much handled, been able to handle everything that I've needed to do.

Int: Ok. So when you have painting and stuff done you get someone else to do that.

C: Yeah. But you see I used to do it but since I had my arm broken, you know,---

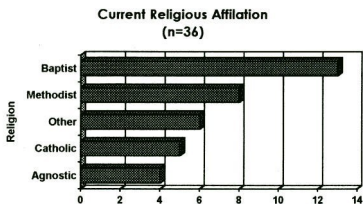
That grass out there need cutting and I don't do that. I do things back in the house.

The majority of the caregivers had little trouble participating in simple activities of daily living such as bathing, dressing, daily housework, money management, and shopping for groceries. However, tasks that required intense physical labor or specialized skills such as home repairs, car repairs, yard work and legal affairs required total assistance.

The majority of those caregivers who cared for a person who used a wheelchair required some assistance when conducting physical transfers. In those situations where the caregiver administered medications to a family member, almost all (n=31) were able to do this with no assistance. However, a few (n=3) did require some assistance in administering medications.

Religion and Spirituality

The majority of the caregivers were involved in organized religion. Over one third of the people that we spoke with were Baptist. Six people identified other religious affiliations. These included: Church of God, Presbyterian, Christian Church, Church of Holiness, Protestant, and Davis Temple Home Church.



Of the 36 caregivers, 75% viewed themselves as religious or spiritual individuals. Half of the caregivers attended church on a regular basis. Twenty of the caregivers said that they would like to attend church more often than they are able to.

Int: Okay, you mentioned that you haven't been to church in thirty-seven years. But, one time in thirty-seven years. Would you like to go more often?

C: Yeah, I like to go to church, but I'm not going to leave Cathy in the hands of just anybody, you know.

Sunday morning we go to church if I can get help in time to get him up. Lot of time we don't make it 'cause I don't have help to get him up sometimes.

I would often find that sometimes I couldn't find the solution I couldn't, I didn't know what to do and I would just say well God its in your hands . . . I'm just a very faithful person I'm just a believer.

C: if there is a lot of sickness in my family, or if there is a death, then there's different organizations within the church that will always support us very strongly.

Int: Do they come over?

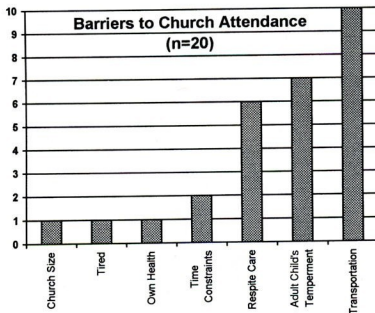
C: ...and bring food, clean houses, do laundry, and things like that.

Int: Ok. Tell me about the kinds of help that you have been getting from your friends and family.

C: Essentially none from friends, and from the family, we begin to get respite help on the weekends, since we moved over here.

The 20 families who did not attend church as often as they would have liked to shared with us why there were not able to attend.

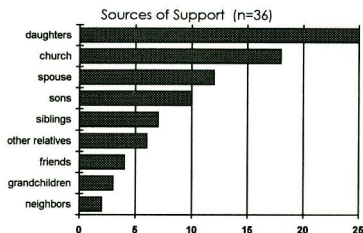
Transportation was the most frequently mentioned barrier to church support.



Sources of Support

We asked these caregivers about the kinds of support that they received from their family members, friends and informal support organizations. The daughters of these caregivers (n=25), were identified as being the most common source of support. For half of the

caregivers (n=18), the church was a valuable source of support in their lives.



The number of people or informal support organizations that these caregivers identified as providing them with support ranged from 0 to 5. Half (n=18) of them identified between three and four sources of support.

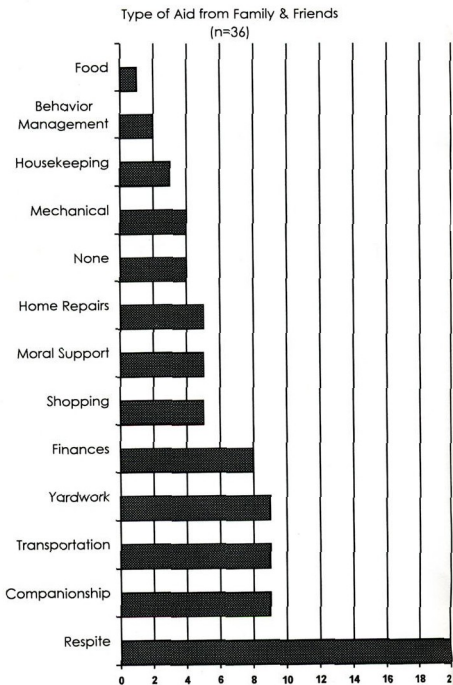
Two thirds (n=24) of the caregivers had supports in their town. Nearly half (n=16) of the caregivers that we spoke with reported having contact with their family and friends at least once a week. The friends and families of these aging caregivers provide them with a wide variety of support services.

I can take her to anyone of them, or even to some of my friends' houses. If I need to go someplace, they would look after her, because they know her, you know. They would take care of her until I got back. I mean, I have plenty of people like that because they know her. And they know how sweet she is.

Well, I have two daughters close enough that if I needed help, one could be over here in probably 10 minutes.

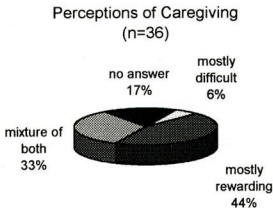
Then I have ministers who are good friends of mines who in time of crisis would, would counsel and just be with me generally.

Well, mmm, I think that, I don't know really how to say this but he just, he is a joy to me, I think the Lord gave him to me. I don't feel *guilt* I did anything to get him--I think the Lord blessed me in giving him to me. He has taught me patience, he's taught me humility, he's, me and the Lord have got really close--since I've had him--- to me he's just so special, you know,



Joys and Burdens of Caregiving

Caregiving, like other aspects of life carries with it both joys and burdens. We asked each of the caregivers how they perceived their role as a caregiver. Was it mostly rewarding, stressful or somewhere in between? The majority (44%) shared that they viewed caregiving as mostly rewarding.

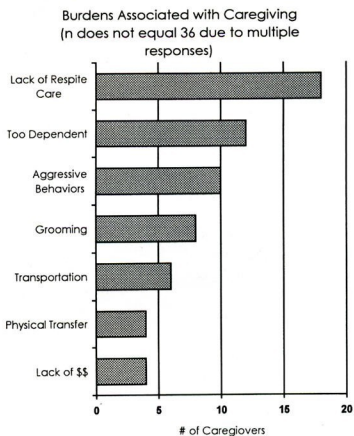


All but two of the caregivers that we spoke with were able to talk about some joyful aspect of caring for their son or daughter. Four of the caregivers viewed their role as a spiritual blessing.

Well, the biggest joy is in knowing that I am here for Geraldine. And I don't know of any other person that understands a handicapped person as well as their parents do. And it gives me pleasure again, to say that I know, to say that I'm here for her. Because I can visualize, what would Geraldine do when she were to come in, and I weren't here? So I count it a blessing to have Geraldine. All of these years that I've been by myself, she is a blessing to me everyday.

In addition to the joys, the burdens that the caregivers experienced were also numerous. Only one person said they did not experience any burdens in their life as a result of being a caregiver.

I hate to clean, and to move her, if she ever falls, I can't get her up. I have to have some help or let her pull her up to a chair to help her get up.



Future Care Plans

Perhaps the most difficult questions that we asked these individuals were about their plans for their son or daughter in the future. We

recognized that this was an extremely difficult area for people to talk about. Each caregiver shared their thoughts about their son or daughter living in a variety of living situations, ranging from living independently to living in a residential facility. The majority of caregivers indicated that they would prefer that their son or daughter be cared for by a member of their immediate family.

<i>Living Situation</i>	<i>Number of Parents Approving</i>
Immediate Family	20
Supported Living Environment	18
Group Home	13
Nursing Home for people with developmental disabilities	11
Nursing Home	8
Foster Home	7
Friends	6
Independently	6
Distant Family	5
Residential Facility	4

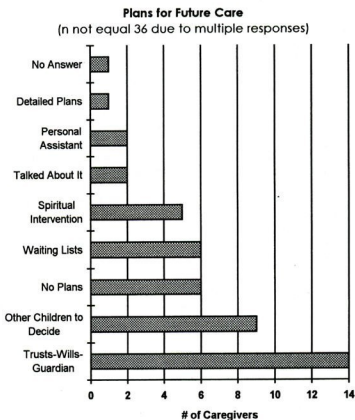
I think the most difficult thing is that my husband and I don't have the time that we would like to--as much time as we would like to have to do some of the things that we would like to do. I think that when you reach a certain age, you sort of sense well that's a chance to be a little bit freer and go and do some of the things that you want to do. And our sense about that is that we don't want to deprive her of her job and the things that she does because she doesn't have the many thrills of life that some of us do have, so to be very specific, it is the fact that I would like to have more time with home in our later life that we seem not to be able to have.

I think it is a day to day thing. I think you have to work through it a day at a time. I really do.

Well, I just hope she'll keep on--20-30 years from now I just hope she's doing the same thing she's doing now, but maybe more in it-- If I by chance that we live I hope that she can be more independent and can be able to do more for herself.

I'm prayin' that God will take Richard before I can't take care of him. And if there's a God he will! (pause) And if he don't there's not one!

The caregivers spoke to us about the plans that they had made for the future care of their adult son or daughter. Six of the parents had made no plans at all. One person did not feel comfortable discussing this subject matter with us. Five caregivers were looking for some spiritual intervention that would either heal their son or daughter or allow their adult child to die first.



We also asked them about the consumer's involvement, if any, in the development of these plans. Over half of the caregivers indicated that they had not discussed these plans with their adult son or daughter. However, nearly an equal number of caregivers felt that the plans that had been made would be satisfactory to the consumer as well as the caregiver.

We recognized that making these plans is extremely difficult for parents for a number of reasons. We wanted to know what supports could be offered to help make this job easier. Nearly a third of the caregivers did not know what supports could be provided to them that would make this task any easier.

Int: Have you talked any of this over with Scotty? Or tried to explain---

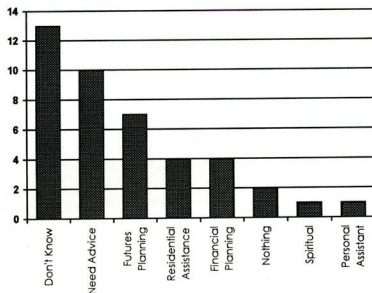
C: Oh, no, no. I can't get that through to him, you know I can remember when I first, when my husband died, you know, I sat down and tried to tell him that concept just didn't reach him

I wish there was something that we could see in black and white or have down that we knew what was available. ... we go to meetings when we hear of anything that has anything to do with housing or anything like that but if there's a waiting list or if there's nothing there or if they're all full, what do we do? How do we find out?

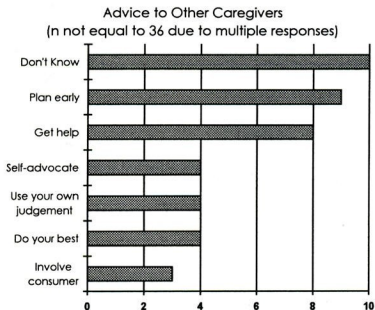
I think the Lord gives you common sense to take use of what's available for Jordan and to get out there and find out what's available for him and, you know, to really care about his needs. And sometimes you, well most of the times you have to put his ahead of yours and, uhh, but, you know, just to be concerned about him and see that he gets what he needs

Oh, the one, one thing that would be good is to know exactly how the group homes and the care system works so far as residential housing and so forth. Everything else, so far as I'm concerned right now is secondary.

Supports needed for future care
(n does not equal 36 due to multiple responses)



We asked each of the caregivers if there was any advice that they could give to other parents of sons and daughters with developmental disabilities about making these plans. Fifteen of them either did not have an answer or said they could not offer any advice because what they needed themselves was advice.



Int: Is, is there any advice you could offer to other caregivers for making plans for the future? Or in general any advice for other caregivers? To help them?

C: No, I need some advice myself...

Services Received and Services Needed

While these caregivers had access to a wide variety of services through formal organizations, the majority of caregivers viewed the developmental service center as the most valuable service that they were receiving. We asked the caregivers about 20 different types of services. Transportation services were received by almost half of the caregivers. Home repairs and respite care were the service needs identified most frequently.

SERVICES UTILIZED AND NEEDED

Comparative Rankings of Services Used and Needed

SERVICES UTILIZED

<u>Relative Ranking</u>	<u>Services</u>
1	transportation
2	case management
3	advocacy
4	SSI
5	home health care
6	respite care
7	recreation/leisure
8	legal assistance
9	counseling
10	assistive devices
11	adult day care
12	home repair
13	housing
14	meal services
15	medical
16	companionship
17	administrative
17	homemaker
17	family support
17	future care

SERVICES NEEDED

<u>Relative Ranking</u>	<u>Service</u>
1	home repair
2	respite care
3	companionship
4	transportation
5	homemaker
6	medical
7	recreation/leisure
8	housing
9	adult day care
10	legal assistance
11	family support
12	counseling
13	case management
14	advocacy
15	assistive devices
16	future care
17	SSI
18	administrative
19	meal services
20	home health care

CONCLUSIONS AND POLICY IMPLICATIONS

THE NEED FOR QUALITY RESPITE CARE PROGRAMS

Recommendations: *Additional flexible*

respite care services need to be made available to aging caregivers of individuals with developmental disabilities. In addition, mechanisms need to be found to inform these individuals of the respite care resources that are currently available and to provide them with the support needed to access those services. Continuing education and training opportunities need to be made available to those who are providing respite care. Communication and cooperation between respite care and caregivers needs to be enhanced.

Our feeling is that we like to know the people that we leave in our home with JJ and we like for them to know JJ ... Its mostly evening care that we can get but it would be good to know someone who could provide some daytime respite care.

THE NEED FOR HOME MAINTENANCE/REPAIR SERVICES

Recommendations: *Additional home repair*

If I had even, if I had a good person that could help me one day, or one half-day a week, you know, regularly, to come in and help with the heavy stuff. I'm gonna have to find somebody to take care of my yard this year, ... cutting grass is a good thing to give you a heart attack.

supports need to be made available to aging caregivers of individuals with developmental disabilities. In addition, more effective ways need to be found to inform these individuals of the home repair supports that are currently available. Finally, legal support should be provided to those whose repairs are not being made for them by their landlord.

THE NEED FOR COMPANIONSHIP

Recommendations: *There is a need to develop*

Yes, that would be wonderful. Especially for TT. You know he plays chess, he plays cards, and he would just love to have someone come in, you know, and even just talk with.

and offer opportunities for companionship for both the caregiver and the family member with a developmental disability. Creative and innovative ways of providing companionship and support to the caregiver need to be developed, such as telephone support groups which allow people to converse without having to leave home and respite care and transportation to allow visits with friends.

THE NEED FOR TRANSPORTATION

Recommendations: *There is a need to assist*

communities in developing creative transportation options that are available, accessible, affordable, and flexible for both the caregivers and their family members with developmental disabilities.

... usually, those things don't go at the time you have to go. And we don't fit the criteria for anything that's out there now. There was one, but you had to be Medicaid eligible to get any service from it. And he was not Medicaid eligible.

THE NEED FOR ASSISTANCE IN DEVELOPING FUTURE CARE PLANS

Recommendations: *There is a need to*

develop creative and innovative ways of informing caregivers and family members with developmental disabilities about the resources that are available to them in their communities and throughout the state. Supports need to be developed that assist caregivers in the development and maintenance of future care plans for their family member with a developmental disability.

Well, the problem is, you know if you make any arrangements in a will or anything else that during the time that's available, this SSI or whatever else would be counter-productive. And that's part of what needs to be changed somehow.

THE NEED FOR FINANCIAL REFORM

I'm hoping the social program will be to the extent that, that provisions will be made for people such as JJ. I'm hoping that as you down size institutions that the dollar values will go back to the persons who needs it, but [the cost of institutionalizing] JJ is astronomical [compared to] what it would cost to provide for her. A whole lot more than it will ever provide if you make those dollars follow her right on to the house.

Recommendations: *Additional flexible financial supports need to be made available to aging caregivers who are providing in home care for family members with developmental disabilities. In addition, more effective mechanisms need to be found to inform these individuals of the financial resources that are currently available and to support them in accessing these resources.*

THE NEED FOR ACCESSIBLE AND AFFORDABLE HEALTH CARE

One thing that hurts is diapers. Sara uses diapers, and they are expensive. I had been using just a cloth diaper. I sew two together and buy huggies and put in it. Of course that's expensive too. But the visiting nurses, they bring seven diapers a week for her; that's what they provide every week. But that doesn't go very far.

Recommendation: *Additional flexible health care supports need to be made available to aging persons with developmental disabilities. Education needs to be provided to doctors in both rural and urban areas so that individuals with developmental disabilities can receive quality healthcare in their local communities.*

INFORMATION AND ACKNOWLEDGMENTS

This is an abridged edition of a comprehensive report by the same authors entitled "The Consumer Discovery Process: Aging Caregivers of Individuals With Developmental Disabilities." The original report contains detailed information on the background of the study, methods, and research instruments used, results obtained, and recommendations. A copy of the comprehensive report may be obtained for \$12 by writing to the University Affiliated Program, University of Georgia, 850 College Station Rd., Athens, GA 30602.

Gratitude is expressed to the faculty and staff of the University Affiliated Program, The University of Georgia, and the Gerontology Center for providing leadership and support throughout this project; to the Governor's Council on Developmental Disabilities for the funding of this project; to the numerous agencies, organizations, and entrepreneurs who helped us form partnerships with the individuals we spoke with; and most importantly to the older caregivers who shared their hearts, their stories, and their lives with us.

THE UNIVERSITY AFFILIATED PROGRAM for Persons with Developmental Disabilities

Believes:

- **Individuals, families, and communities** are unique and have inherent value. We are all strengthened when that uniqueness is recognized, respected, and nurtured.
- **Individuals and families** have the right to information, their own definition of needed supports, options for choice, and the right to exercise control over their own lives.
- **Individuals and families** need to be connected to their communities in ways that enhance their own roots and history, and strengthen the capacity of communities to respond
- Supports and services for **individuals and families** can be developed that are flexible, responsive, non-intrusive, and non-judgmental, and which nourish and enhance local involvement and ownership.
- **Individuals** have the right to define their own needs, to have opportunities for growth and self-determination, to risk and to make mistakes, and to define their own quality of life.
- **Individuals** have the right to equal opportunities to meet their own basic needs, and the right to participate in all aspects of community life free from attitudinal and physical barriers.
- While **family** is defined in many ways, its essence is unity. The family unit is to be recognized as the primary focus of support, commitment and love.
- **Communities** have the responsibility to provide equal opportunity for participation in all aspects of community life.
- **Communities** have the capacity to meet human needs and to foster opportunities for awareness, relationships, and action that strengthen independence, interdependence, and community resourcefulness.
- **All** people have gifts to bring to community life.

"Adapted from the Beliefs Statement of the Governor's Council on Developmental Disabilities for Georgia."