

**South Carolina  
Department of Disabilities and Special Needs**

**Stakeholder Analysis**

September 2012

**South Carolina Department of Disabilities and Special Needs  
Stakeholder Analysis**

**Table of Contents**

Executive Summary .....	iii
Background .....	1
Families with Children Birth to Age Five at Home .....	1
Table 1. Parts of Current Support System Meeting Child’s Needs .....	3
Table 2. What DDSN Can Do to Create or Improve Supports for Child .....	5
Table 3. What DDSN Can Do to Improve the Value of Supports for Consumers and Families .....	6
Families with School Age Children, Ages Six to Twenty Years .....	10
Table 4. Parts of Current Support System That Work Well .....	12
Table 5. What DDSN Can Do to Create or Improve Supports for Child .....	13
Table 6. Important Considerations When Transitioning Out of the School Environment .....	16
Adults or Children Who Live in DDSN Residential Settings .....	18
Table 7. Most Important Supports .....	19
Table 8. Parts of Current Support System Working Well .....	23
Table 9. What DDSN Can Do to Improve the Value of Supports to Individuals ...	24
Table 10. What DDSN Can Do to Improve the Value of Supports for Consumers and Families .....	26
Table 11. How Cost of Services Can Be Better Contained .....	27
Table 12. Concerns/Barriers to Appropriate Healthcare .....	29
Table 13. What it Would Take to Live More Independently .....	31
Adults Living With Families .....	33
Table 14. Most Important Supports .....	34
Table 15. What DDSN Can Do to Improve the Value of Supports to Individuals	38
Table 16. What DDSN Can Do to Improve the Value of Supports for Consumers and Families .....	40
Table 17. What Comes to Mind When Thinking About Health Care for Yourself or Family Member .....	42
Table 18. Supports Needed to Continue Care in Your Home .....	43

Table of Contents

- cont. -

Stakeholders Online Survey Results .....	44
Table 19. Characteristics of Online Survey Respondents .....	46
Families with Children Birth to Age Five at Home .....	45
Families with School Age Children, Ages Six to Twenty Years .....	45
Adults or Children Who Live in DDSN Residential Settings .....	47
Adults Living With Families .....	48
Summary .....	49

## Executive Summary

As part of its continuing efforts to improve the services it provides its clients, the South Carolina Department of Disabilities and Special Needs (DDSN) conducted a series of eight focus groups with each including various stakeholders: (1) families with children birth to age five at home; (2) families with children age six to twenty at home; (3) adults or children living in a DDSN residential home; and (4) adults living with families. Across the state, 805 people participated in these groups. Topics covered in these sessions included most and least important supports; parts of the support system that are working well or that need improvement; how DDSN can improve the value of the supports it provides; cost containment; health care concerns and barriers to appropriate health care; and additional supports needed. In addition to the focus groups, DDSN posted an online survey for stakeholders designed to investigate many of the same issues addressed in the focus groups; 150 stakeholders completed this survey. The major findings from this project include:

(1) Virtually every service that DDSN provides is considered important by consumers. This is evidenced most vividly in the responses of the focus group for adults living at home during which an extensive range of services were described as “most important,” but it is evident in the other groups as well. Stakeholders need the services and supports that DDSN provides and they consider them to be important. While the identification of the “most important” service varies across groups, respite care, quality staff, and service coordination are generally considered important. Important supports for different groups vary by circumstances. Early intervention therapies are more important to those with children birth to age five, while personal care aides are mentioned more frequently by those with children ages six to twenty, respite care is more often needed by families with adults living at home, and quality of life measures and compatibility with other residents are more important to stakeholders with a family member in a DDSN residential home.

(2) There are virtually no supports that are considered to be “least important.” Although several individual services were mentioned as part of these groups or in the survey, the sentiment clearly expressed was that “all services are important.” The one support that was mentioned most frequently as least important was the annual life plan.

(3) Stakeholders generally believe that the DDSN system works well. Aspects of this system that were perceived to be working well varied by living situation. Those with children from birth to age five felt that Pervasive Developmental Disorders waiver services and service coordination worked well; those with school-age children ages six to twenty cited waivers and family supports; those with adults living at home identified the consumer focus and consistent services as features that worked well; and those with a family member in a residential setting cited features of the home, such as cleanliness or safety, as well as the quality of care provided.

(4) The most frequently identified ways in which DDSN could improve the supports it provides were training of staff, continuity of care, assuring the quality of services, and providing additional funding.

(5) Stakeholders offered a number of suggestions for containing costs. Many of these were general suggestions such as to use best management practices or to monitor costs. Specific suggestions included using more technology, using more fuel efficient vehicles and combining trips, and using more volunteers to provide services.

(6) Health care concerns consistently identified included the need for more providers who accept Medicaid; more services that would be covered by Medicaid; the need for more providers; the need for more specialists; and more choice in providers. Concerns about dental care were also expressed across groups.

(7) Throughout these groups, participants expressed the importance of communication. Communication about available services, communication with physicians, communication between family members and DDSN staff, and between DDSN and the community were among the types of communications mentioned as important.

(8) Although the value of and need for communication was expressed in a number of the items considered, it was particularly important in transition planning. Stakeholders wanted to know the types of services that were available. The need for planning for any transition, as well as the need for service coordination throughout the process, were considered important.

# **South Carolina Department of Disabilities and Special Needs**

## **Stakeholder Analysis**

As part of its continuing efforts to improve the services it provides its clients, the South Carolina Department of Disabilities and Special Needs (DDSN) conducted a series of eight focus groups with each including various stakeholders: (1) families with children birth to age five at home; (2) families with children age six to twenty at home; (3) adults or children living in a DDSN residential home; and (4) adults living with families. Across the state, 805 people participated in these groups. Topics covered in these sessions included most and least important supports; parts of the support system that are working well or that need improvement; how DDSN can improve the value of the supports it provides; cost containment; health care concerns and barriers to appropriate health care; and additional supports needed. The comments from these sessions were transcribed and provided to the University of South Carolina's Institute for Public Service and Policy Research (IPSPR), which was commissioned to analyze this information. In addition to the focus groups, DDSN posted an online survey for stakeholders designed to investigate many of the same issues addressed in the focus groups; 286 started this online survey and 150 of them completed it. This report provides a summary of the positive and negative aspects of DDSN that were observed in each of these four groups, as well as those reported in the online survey. The final section of this report presents a synthesis of the information from these various sources.

### **Families with Children Birth to Age Five at Home**

Stakeholders of young children, birth to five years old, identified a number of different supports as most important to them. The support that was most frequently mentioned was early

intervention therapy. Several participants mentioned coordination of services as most important and assistance with waivers was also cited several times, as was assistance with insurance or co-payments. Other supports that were mentioned included family therapy, special instruction, parent-to-parent support, genetic testing, medical support, transportation assistance, and support for parents to be given a break from care giving responsibilities.

As was the case with the question on most important support, participants did not identify any particular support that was least important. In fact, many of the responses to this question cited some problem – i.e., having to be on a waiting list for a year or programs whose stipulations are too stringent – and did not mention a specific support that was thought to be least important. Specific services that were mentioned were Level 2 services; life planner; counseling or social work services; education or counseling for children; and "services provided by staff who are not highly trained."

Stakeholders of children from birth to age five at home most frequently mentioned early intervention services as the part of the current system that is working well (see Table 1). Focus group comments included the sense that Early Intervention provided consistent training and support, that the coordinators were well-trained, and the program develops a rapport with the entire family and does not just serve the child. Pervasive Developmental Disorders was also cited several times as a feature of the system that is meeting the child's needs. Other parts of the current support system that those participating in the small group discussion considered to be working well included: respite care; personal care aides; school; therapies; access to resource materials; service coordination; the 3 year-old transition program; support services; Tax Equity and Fiscal Responsibility Act provisions; and the perception that the system is open and receptive to input from clients.

TABLE 1  
PARTS OF CURRENT SUPPORT SYSTEM MEETING CHILD'S NEEDS  
CHILDREN BIRTH TO FIVE YEARS OF AGE

Early Intervention

- Consistent training and support from Early Intervention
- Well-trained Early Intervention coordinators
- Early Intervention developing rapport with the entire family, not just serving the child

Pervasive Developmental Disorders

- Pervasive Developmental Disorders - Applied Behavior Analysis

Respite Care

Personal Care Aide

School

Therapies

Access to resource materials

Service coordination and team cohesion

3 year-old transition program

Tax Equity and Fiscal Responsibility Act

Support services

Open system; receptive to input

The information displayed in Table 2 provides the responses of focus group participants to the question of what they would like DDSN to do to create or improve supports for their child. The most frequently mentioned improvement involves service coordination, including better transition from Early Intervention to Service Coordination, better education so that the family can serve as their service coordinator for school issues, and additional supports so that the "at risk" population can transition to service coordination. A number of participants had suggestions related to communication, including increasing awareness of resources available, in particular among the Hispanic population, as well as better communication with physicians and increasing their awareness of services. There were two mentions of reducing the waiting list, one specifically for Head Start, as a way to improve supports. Other suggestions for creating or improving the supports that DDSN provides included more therapy providers, more childcare training, more funding for respite care, more funding options for summer services, and improving Head Start.

The question that generated the most responses among this focus group was that on how DDSN can improve the value of what it does to support its consumers and families. These responses, presented in Table 3, indicate that while these participants felt that Early Intervention was an aspect of DDSN's services that is working well, they also have a number of recommendations for improving its value. Among the observations recorded were that Early Intervention needs more funding; that there should be more training for Early Intervention providers; and that there should be more consistency among Early Intervention providers.

Several suggestions for improving the value of the supports that DDSN provides to consumers and families mentioned service coordination, including better training for service coordinators and the need for more continuity with Service Coordinator providers. Waiting list concerns were also mentioned by several participants, including the suggestion that it would be

TABLE 2  
WHAT DDSN CAN DO TO CREATE OR IMPROVE SUPPORTS FOR CHILD -  
CHILDREN BIRTH TO FIVE YEARS OF AGE

Better transition to Service Coordination

- Better education for the family to help them be their own best service coordinator for school issues
- More consistent service coordination for the 6 - 12 year old population
- Provide additional support for the “at risk” population so that they can transition to service coordination
- Better transition from Early Intervention to Service Coordination; Early Intervention phasing out or Service Coordination staying involved longer at beginning

More contact once transferred to Service Coordination/Level II

Single point of entry

Better communication with pediatricians (e.g., “Place for Me” gives information packets)

Physicians to learn about services

Increase awareness of resources (e.g. TEFRA, Medicaid, BabyNet)

- Get the word out they are there
- Increase awareness among the Hispanic population

Better referral system

More efficient way of getting updated BabyNet provider listings

Waiting list needs to go down

- Waiting list for Head Start

More therapy providers

More childcare training

Improve Head Start

Need more funds for respite care

More funding options for summer services

Parent advocacy

Address turnover (in Early Intervention and Service Coordination)

DDSN should partner with other organizations

TABLE 3  
WHAT DDSN CAN DO TO IMPROVE THE VALUE OF SUPPORTS FOR CONSUMERS  
AND FAMILIES - CHILDREN BIRTH TO FIVE YEARS OF AGE

Early Intervention

- Need more funding for more Early Intervention
- Additional training for Early Intervention providers
- Ensure Early Intervention providers are ready to serve kids and their families
- Keep quality Early Intervention; make caseloads more manageable
- More consistency with respect to competency and motivation among Early Intervention providers
- Early Intervention supervisor satisfaction surveys
- Have families interview Early Intervention providers
- Education and support for Early Intervention providers to educate families about benefits to help them make better decisions
- There are a lot of new Early Intervention providers - Have their backgrounds been checked?

Service Coordination

- Better training for Service Coordinators
- Need more continuity with Service Coordinator providers

Service Coordinators and Early Intervention providers should explain to families what they are signing up for (Pervasive Developmental Disorders, etc.)

Waiting List

- BabyNet waiting list for therapy is too long
- Waiting list for care is too long
- Would be good to have someone to work with families while on waiting list

Training

- Provide funding for training
- Regional or local training may help with consistency of services provided
- More opportunities for staff development

Communication

- Need more education and communication about what DDSN has available
- Information needs to be more readily available
- More awareness of services and networking

Quality case management

Need more medical providers

Sibling/family counseling

TABLE 3

- cont. -

Focus on Early Intensive Behavior Intervention pre-school aged children

More flexibility with accommodation of individual or family needs. For example, location; ability for providers to have more authority when service needs are questionable or there are "no shows" for services (sliding fee scale)

BabyNet rate is too low for Applied Behavioral Analysis

Cost drive – annual eligibility for BabyNet is going to drive cost up

Case management is valuable

Higher caseloads are not cost effective

Appropriate use of service delivery based on need

Family support funds can be valuable if there are any available

Establish clear guidelines for professional behavior

Less paperwork, more electronic processing

Interpreter logs directly to DDSN

County differences on how things are done – children are treated equally county to county

In Woodruff everyone gets \$4,000 – no qualifications

Stop relying on the government for funding; work together in the community to make the most of our money

Private provider would like to be kept up to speed about what resources are available on an ongoing basis

good to have someone to work with families while on the waiting list. Stakeholders also identified training and communication as areas in which DDSN could improve its services. Group comments indicated that more funding should be provided for training, that regional or local training would provide more consistency in service provision, and that there should be more opportunities for staff development. In terms of communication, participants felt that DDSN needed to do more to inform people about the services that are available.

Other individual suggestions for potential improvements included quality case management, more medical providers, sibling or family counseling, and a focus on Early Intensive Behavior Intervention for pre-school aged children. Establishing clear guidelines for professional behavior, having less paperwork and doing more electronically, and providing more consistency across counties were also cited as ways in which DDSN could improve the value of the supports it provides to consumers and families.

Another question of interest to DDSN concerned how costs can be contained. Stakeholders of young children, birth to five years old, provided a number of suggestions for containing costs, including eliminating paperwork and doing more electronically and eliminating redundant forms. Administrative procedures – quality assurance, monitoring of services, reducing caseloads, and more efficient service delivery – were cited by the group, as were features of the system such as stricter eligibility criteria, addressing inconsistent families, and limiting the number of emergency visits.

The main concern that these stakeholders expressed about health care involved providers, specifically the availability of providers, the need for quality providers, the lack of Medicaid providers, and the need for specific providers, such as therapists or BabyNet providers. Several comments addressed care coordination, particularly for medically complex children, and there was

concern voiced about duplicated procedures. This group also mentioned acceptance of Medicaid by providers and Medicaid reimbursement rates being too low as concerns related to health care. Three barriers to receiving appropriate health care were identified: the application process for assistance; Tax Equity and Fiscal Responsibility Act provisions; and waivers. The parts of health care services that participants thought were working well included medical homes; support of the family, specifically educating families about health care; being able to find a provider in urban areas and in other states, if necessary; and services through the Tax Equity and Fiscal Responsibility Act.

The final topic addressed in this focus group session was transitioning, including the features that were important in transitioning, those that are working well now in the transitioning process, and improvements that are needed. Although the responses were fairly individualized, the theme expressed the need for continuity or consistency: keeping the same Early Intervention specialist from birth to five years old; continuity of occupational therapy, physical therapy, and speech services; continuing the same service; and consistency among counties. Standardized screening and evaluation, information on services available, and coordination among all parties involved were also seen as important in a smooth transition. Transportation to school and the need for ongoing training were also mentioned as important for transitioning.

Five features were mentioned as working well in the transition process now. These included Early Intervention specialists participating in the Individualized Education Program; the fact that most of the time, services begin at age 3; and communication. The relationship that the parent has with the school is also seen as important in the transitioning process.

In terms of improvements to the transition to school, the most frequent response involved the need to improve coordination and communication among the organizations involved, and

several of these mentioned BabyNet, including the need to strengthen the relationship between the Board of Education and BabyNet; eligibility for BabyNet; and BabyNet intake coordinators telling families that their “kids probably won’t qualify” at the beginning of the process. A second theme for improvement involved information and communication, including better communication with Head Start; access to resources for both parents and professionals; more information provided about Pro-Parents; and information about Department of Education contracts. Consistency across school districts and providers and better coordination during summer months were also mentioned as ways to improve the transition to school process.

### **Families with School Age Children, Ages Six to Twenty Years**

The results of the focus group of stakeholders with children ages six to twenty on the question of most important supports were similar to those from the focus group for younger children in that no single support was generally viewed as most important, but different in that the types of supports identified varied. The support most frequently mentioned was related to caregiver services: respite care was mentioned by several participants and other supports cited included caregiver services, day services, a school or home aide, a personal care aide, and support during the holidays. Behavior related supports were also seen as important, including behavior intervention and Applied Behavior Analysis therapy. Medical supports, including psychiatric care and nursing services were identified as important supports, as were case management and service coordination. Other supports that were mentioned included waiver support for Pervasive Developmental Disorders and specialized equipment, job training, assistive communication technology, and summer camp.

This group’s responses to the question of the supports which are least important did not necessarily address this issue, but rather identified problems in the system or made general

comments about the importance of the program. For example, one comment stated the need for more day options and another noted that work is important for self-esteem, while other comments included the belief that all services or a specific service was important. One participant felt that case management was the least important support and another felt that community service projects take away from providing real service.

Comments made in reaction to the question of the parts of the current support system that are working well are presented in Table 4. Two features that received several mentions were family supports and waivers. Participants were positive about the features of the system that let families choose from a list of services, the flexibility of services for families, and getting equipment directly to families, and there were two comments about the waiver aspects of the system working well. Other features, such as specialized nutritional diets, the special needs roadmap, and communication with the educational system were also mentioned.

As the information in Table 4 indicates, this question elicited almost as many comments about features of the support system that were not working as those that were. Although no specific feature was mentioned multiple times, participants expressed concerns about supports ranging from a perception that the Pervasive Developmental Disorder waiver is not working well or that personal care assistants are not trained, to not being able to take nurses on road trips or the program not covering the cost of diaper inserts.

When the discussion with stakeholders with children ages six to twenty turned to the questions of what they would like DDSN to do to create or improve supports to individuals and how DDSN can improve the value of its supports to consumers and families, participants again offered a range of responses. The entries presented in Table 5 indicate that information and communication is an area in which DDSN could improve the supports it provides. Suggestions

TABLE 4  
PARTS OF CURRENT SUPPORT SYSTEM THAT WORK WELL  
SCHOOL AGE CHILDREN, AGE SIX TO TWENTY

Family Supports

- Let families pick and choose from list of services within the dollar cap
- More flexibility of services for families
- Equipment getting directly to families

Waivers

- Waiver waiting lists services
- Waiver support service

Equipment

Diaper quality/wipe quality

Equipment approval

Therapist pay

Communication with the educational system

Special needs roadmap

Adding items currently not covered

Specialized nutritional diets

Population is clearly identified

More individualized services, not cookie-cutter

Comments about aspects of the system that are not working well

Pervasive Developmental Disorder Waiver is not working well

Respite pay not worth the training requirements

Respite workers not getting hours

Cannot take nurses on road trips to the park, store, etc.

Need improved markup for durable medical equipment provider; get rid of middle man

Improve service coordination and the ability to conduct good assessment

Personal care assistants are not trained

Will not cover diaper inserts

Would like more direct way for getting authorization and approval

TABLE 5  
WHAT DDSN CAN DO TO CREATE OR IMPROVE SUPPORTS FOR CHILD -  
SCHOOL AGE CHILDREN, AGE SIX TO TWENTY

Information/Communication

- Comprehensive website with detailed information
- Make information available to doctors and parents
- Make a list of all services
- Better communication about services
- Ask the community, organizations and churches to get the word out about services

Cost related supports

- Less administrative fees
- Be more cost efficient; e.g., UPS sends one item when durable medical equipment company forgets one item in order
- Some families stockpile; better in-home monitoring/family training needed to reduce costs
- Lobby the legislature for funding

Access

- Improve access to service coordinators
- More contact with case manager

Connect parents to support and advocacy organizations

Empower family to make choice of providers

Expand day supports

Educate service coordinators; e.g., how to get legal authority once clients are 18 years old

Make waivers more sensible

Get the funding; let the family manage order or shift to another service as needed

Need more therapies; need at least one per week

Look at practices in other states

Medical records

Improve responsibility for ordering supplies; base on need, not on fear of losing services or supplies

in this area included a comprehensive website with detailed information on services, providing a list of all available services, making information available to doctors and parents, better communication about services, and asking other organizations to assist DDSN in publicizing the services it provides.

A second area for which there were several suggestions for improvement had to do with various aspects of costs. These included reducing administrative fees; becoming more cost efficient; improving in-home monitoring or family training to reduce costs; and improving responsibility for ordering supplies. A related suggestion involved lobbying the legislature to secure more funding. There were also two comments related to access to services, one involving more access to service coordinators, the second seeking the ability to see case managers more frequently.

Other suggestions for creating or improving supports noted in this group included expanding day supports, empowering families to make the choice of providers, and providing more therapies. Additional comments included better education for service coordinators and looking at practices in other states.

Participants in this group also offered a variety of suggestions for how DDSN could improve the value of what it does to support consumers and families and better contain costs.

Two of these involved Medicaid, one suggesting that schools should use Medicaid for occupational therapy, physical therapy, and speech services and the second that Medicaid should be used directly to provide services. Another comment was that families could benefit from a better understanding of the cost structure of providing services. Specific ideas for improving cost containment included the use of voucher systems for wipes, diapers, and equipment; ongoing

quality assurance to avoid price gouging; eliminating the middle man for durable medical equipment; and the use of video conferencing to educate families and providers.

The focus group discussion among stakeholders of a school age child between the ages of six and twenty also identified a number of concerns when considering the questions of obtaining health care for themselves or a family member and concerns about access to health care. One concern identified was the need for more providers and the need for a greater choice of providers. Several comments expressed concerns about dental care while another cited the need for mental health services for family caregivers. One participant said that it was hard to transition from pediatricians to adult specialists, while another believed there was a problem in that many physicians do not accept Medicaid.

Other features that people thought of related to obtaining health care were more specific and included items such as improving health and nutrition education, improving the quality of incontinence supplies, and problems in waiting for the Medicaid van. More general comments expressed in the discussion of this question included the need for family members to take ownership for health care, that caregivers need good medical care themselves, and a belief that families should not be encouraged to drop insurance as the child gets older.

Several of these concerns were also expressed in terms of access to health care. These included medical care professionals not accepting Medicaid, transitioning to adult providers, and the lack of special needs expertise in the area of mental health. Other concerns about access to care expressed were about the availability of Department of Juvenile Justice behavioral support to meet transition needs and the use of interns from USC to assist in mentoring.

The things that were identified as important to this group on the topic of transitioning out of the school environment are displayed in Table 6. The most frequently mentioned

TABLE 6  
IMPORTANT CONSIDERATIONS WHEN TRANSITIONING OUT OF THE SCHOOL  
ENVIRONMENT - SCHOOL AGE CHILDREN, AGE SIX TO TWENTY

Jobs related

- Job training
- More options for jobs training
- Employment
- More employment choices
- By law, job training should be in the individualized education program

Education

- Continuing education
- Life skills training

Activities

- Day programs
- Meaningful activities

Department of Education

- Help Department of Education know what needs to be done in training
- DDSN should push Department of Education

Early transition planning

Financial or legal planning; trusts

Need involvement of service coordinator with families of 15-16 year olds for better assessment and planning

Accountability should be shared; responsibilities divided between the family and the service coordinator

Better assignment of service coordinators to target or redirect resources; better monitoring

Families sometimes burdened with being their own service coordinators; getting their own bids

Annual review does not always occur; then there is a crisis and what happens?

Keep it simple

Families should be contacted twice per month

Hard to get people to return calls

Look at children's primary need and determine what agency should provide case management

consideration in transitioning to schools involved jobs, including more opportunities for job training, more employment choices, and including job training as part of the individualized education program. Several education-related considerations were mentioned, including continuing education and life skills training, and encouragement to DDSN to push the Department of Education and to let them know what needs to be done in training.

There were also several comments related to activities, such as day programs or the need for meaningful activities. Other more specific considerations, such as early transition planning and financial or legal planning were also mentioned, as were operational considerations, such as the need for service coordinator involvement, the division of responsibilities between the family and the service coordinator, and the sense that families are sometimes charged with being their own service coordinators. More general remarks, such as “keep it simple,” “families should be contacted twice a month,” or “it’s hard to get people to return calls” were also expressed during this session.

The final topic addressed in this focus group was what works well now and what needs improvement. The comments made in this discussion were largely focused on suggestions for improvement rather than things that were working well now and these varied across a range of issues. Specific comments included:

- Case managers need to educate families
- Do a better job of explaining choice
- Educate families to empower them to make it happen
- More life skill training needed; there are longer hours provided in the CLTC waiver
- More stakeholder sessions; quarterly
- Parents need to take ownership of the individualized education program

- All school districts should provide the same level of service
- Transition coordinators should start the process early
- Cannot leave school; there is nothing there
- Get on waiver waiting list
- People on receiving end of phone calls are not friendly

### **Adults or Children Who Live in DDSN Residential Settings**

The results from the focus group with stakeholders of adults or children who live in residential settings were more diverse than those from the groups conducted with stakeholders of children. Responses to the question of the supports that are most important to this group can be classified into nine broad categories: quality of life; staff issues; services; family issues; activities; medical care; residential setting; communication; and other. A more complete description of the specific elements within each of these support categories is provided in Table 7.

As this information demonstrates, a wide range of supports are perceived to be important, and there is not one specific support that dominates in terms of importance. One of the most frequently mentioned themes involved the quality of life, particularly safety, independence, and health. Other aspects of quality of life that were mentioned in this group included participating fully in life, no restrictions, having choices, a purpose, and happiness.

Staff was also mentioned a number of times in this discussion, and most of these comments were positive about the support received, such as consistent service, the continuity of staff and lack of turnover, and a caring, friendly, and dedicated staff. Focus group participants also mentioned the need for proper staff and expressed a concern that staff may leave because they are not paid enough.

TABLE 7  
 MOST IMPORTANT SUPPORTS  
 ADULTS OR CHILDREN LIVING IN A DDSN RESIDENTIAL HOME

Quality of Life

Safety (4)  
 Independence; independent living (3)  
 Health (2)  
 No restrictions  
 Quality of life  
 Participate in life  
 Happiness  
 Purpose  
 Choices  
 Relationships  
 Socialization  
 One-on-one time  
 Residents feel staff really care

Staff Issues

Consistent staff (3)  
 Training of staff (3)  
 Continuity of staff (2)  
 Lack of staff turnover  
 Caring, friendly staff  
 Dedicated staff - more than a job  
 Positive relationships with staff  
 Good communication with staff  
 Trust of staff  
 Keep staff that knows consumers the best  
 Must have adequate staffing  
 Proper staffing  
 Don't pay enough to keep staff

Activities

Activities  
 Meaningful activities  
 Field trips  
 Outings  
 Recreation  
 Workshops  
 Productive time  
 Need for exercise

Services

Service coordination (2)  
 Quality of services  
 Level of services  
 Close proximity of services  
 Speech services  
 Money management  
 24-hour service  
 Meeting needs  
 Documentation of needs  
 Reliability across the board

Family Issues

Family participation  
 Family setting  
 Family member input  
 Include siblings  
 Continuity of home location  
 Proximity of home to family  
 Mechanism for families to meet with staff  
 Video of parent's information  
 Residential placement  
 There is no support for families

Medical Care

Good medical care (2)  
 Health care (2)  
 Medical administration by qualified staff  
 Proper care  
 Dental care  
 Medications can be a problem

Residential Setting

Compatibility among consumers (2)  
 Consumers in compatible settings  
 Residential setting  
 Dietary needs  
 Training for residents  
 Moving from Intermediate Care Facility to  
 Community Training Home

TABLE 7

- cont. -

Communication

Communication (2)

Open communication between consumer and staff

Open communication between family and staff

Other

Peers

Supervision

Structure; routine

Community integration

Community interaction

Employment

Bringing more work for consumers to community

Activities for consumers were also identified as an important support as were the services DDSN provides. Among the activities cited were field trips, outings, recreation, and exercise. While several services, such as money management or speech services, were mentioned, many of the remarks about services were about the high quality of services, the proximity of services, the level of service, or service coordination.

Family participation was also viewed as an important support. Elements such as family participation, family input, inclusion of siblings, and proximity were all mentioned as important. There was one negative perception about the lack of support for families.

Related to family issues is the support in residential settings. Compatibility among consumers, meeting dietary needs, the training of consumers in residential settings, and transitioning between settings were each identified as important supports.

Quality medical care was also mentioned a number of times as an important support, as was communication among the consumer, staff, and family. Other features, such as community integration and work opportunities were also cited as part of this focus group discussion.

While these focus group participants were able to identify a wide range of supports that were considered most important, they were reluctant to cite any supports as least important. Most of the reactions to this question were “none is least important” or “everything is important,” and other comments identified concerns, such as too much paperwork or the staff being overwhelmed, rather than supports that were not important. One support that was mentioned was the life plan, with participants expressing the belief that this plan should target more realistic goals, that the family should have more say in the plan, and that there should be more communication between the family and staff.

When asked to consider the parts of the current support system that are working well, these stakeholders of those who live in residential settings cited a number of aspects (see Table 8). The largest number of these were related to features of the home, including its safety, cleanliness, the quality of the food, and the compatibility with other residents. A number of programs were also mentioned, including workshops and day programs, as was the quality of the staff. The health care provided to consumers was cited several times, along with the overall quality of care provided.

Although this group considered many of the current supports to be working well, they provided a number of suggestions for ways in which DDSN could improve the supports it provides to individuals (see Table 9). The most frequent comments were related to staff. Providing higher salaries for staff, decreasing turnover and improving continuity, providing better training, and reducing staff caseloads were among the suggestions for improvement. A number of residential features were also discussed. Several of these concerned the compatibility of placements. Other residential comments were related to the location of the home and more flexible vacation schedules for residents.

Several features of the services provided in residential settings were also discussed. Comments were made about the quality, the range, and the location of services along with the need for specific services such as more person-centered plans, services for the hearing impaired, and behavior plans.

This group also expressed concerns about family issues, particularly assuring the quality of care if a caregiver dies or is no longer able to provide care and the need for future planning. Health care concerns were also mentioned a number of times in this group, specifically, the need to monitor health care, observance of medical needs, staff follow-up on care, and improved psychiatric supports and dental care.

TABLE 8  
PARTS OF CURRENT SUPPORT SYSTEM WORKING WELL  
ADULTS OR CHILDREN LIVING IN A DDSN RESIDENTIAL HOME

Residential Features

Safety and security (2)  
Housing and residential  
Compatibility of residential settings  
Safety, health and cleanliness of home  
Quality of food  
Clean home

Programs

Programs  
Socialization in day programs  
Workshop – Fuji contract  
Workshop – Purpose and Structure

Staff

Great staff  
Staff relationship with consumers  
Caring staff  
Great director

Health Care

Constant checking on medication  
Health care for residents  
Health care

Quality of Care

Caregiving  
Continuity of care – staff and service coordination  
Sense of security by family that family member is cared for

Other

Communication from DDSN staff  
Policies and procedures  
Good family contact  
Babcock manages financials for consumers well

TABLE 9  
WHAT DDSN CAN DO TO IMPROVE THE VALUE OF SUPPORTS TO INDIVIDUALS -  
ADULTS OR CHILDREN LIVING IN A DDSN RESIDENTIAL HOME

Staff

Higher salaries for staff (2)  
Better staff training (2)  
Trusting relationships with staff  
Diversity of staff  
Less staff turnover  
Improve continuity  
Reduce service coordinator caseloads  
Staff should wear ID at all times

Residential Issues

Compatibility  
Compatibility of groups of consumers  
Compatibility of housemates  
Take time to find more compatible placements  
Improve continuity of housemates  
Improve continuity of location  
Location of home  
More creativity in enhancing life skills  
More flexible vacation schedules for residents

Services

Quality of services  
Offer full range of choices to meet needs  
Equality of services among providers  
More person-centered services  
Behavior plans  
Services for hearing impaired  
Location of services

Family Issues

Assuring quality of care if caregiver dies (2)  
Families to be able to see schedule of holidays (2)  
Future planning  
Legal guardianship - guidance to families

Health Care

Monitor healthcare at all facilities  
Increased staff observance of medical needs  
Follow-up by staff on care  
Psychiatric supports  
Better dental care  
Good outcomes for consumers' health

Activities

Exercise programs  
Outings  
Religious activities  
More productive activities

Work/Employment

Better contracts at workshops  
Job coaches; training  
More job coaches  
Workshop does not work well for some

Communication

Lack of communication  
Day vs. residential communication  
Greater awareness of residential services

Other

Waiting list concerns  
Additional resources needed  
Continue to advocate for funding  
IDs needed for consumers when they go out  
Set realistic goals  
Improve providers' quality management

Stakeholders of adults or children living in residential settings also identified activities, employment, and communication as areas in which DDSN could improve the value of supports that it provides to individuals. Activities such as exercise programs and outings, more job coaches and training, and the perceived lack of communication were included in this discussion. Other items mentioned included concerns about waiting lists, the need for additional resources, and continuing to advocate for funding.

When the discussion moved from improving the value of supports for individuals to improving the value of supports for consumers and families, there was some overlap in responses although with a different emphasis. The most frequent comments involved staff, including the quality of the staff, the need for staff to recognize job expectations, and the need for staff to work together. Communication was also viewed as important in improving supports for consumers and families, with the group expressing a desire for more information and better communication from DDSN. More services, particularly person-centered services, and more family involvement also were mentioned in this group.

One theme that emerged in the discussion of supports for consumers and families that was less evident in the discussion of supports for individuals was community involvement. Improving community awareness, getting more community volunteers and connections to the community, more community education, and greater interaction with stakeholders were suggested as ways in which DDSN could improve the value of supports for consumers and families.

Better management was the predominant theme when this group entertained the question of how the cost of services can be better contained (see Table 11). Among these suggestions were quality management; monitoring the inventory of products; reviewing the system for potential cost savings; bulk purchasing; and reducing paperwork.

TABLE 10  
WHAT DDSN CAN DO TO IMPROVE THE VALUE OF SUPPORTS FOR CONSUMERS  
AND FAMILIES - ADULTS OR CHILDREN LIVING IN A RESIDENTIAL HOME

Staff

Quality of staff  
Drug test results prior to beginning training  
Random drug testing  
Staff should recognize job expectations prior to being hired  
Reduce duplication of staff  
Nurses and residential staff need to work together better

Community Involvement

Improve community awareness  
More volunteers and more connection to community; e.g., churches, schools  
More community education  
Stop discouraging volunteer participation  
More interaction with stakeholders

Communication

More information from DDSN Boards to keep people informed  
Better communication from management  
Share information about support services  
Periodic visits by DDSN staff to residences

Services

More person-centered services – find out what the people want  
Funding day support slots via band system  
County boards should provide more supports

Family Issues

Get more involvement from family members  
Facilitate more family involvement with individual consumer

TABLE 11  
HOW COST OF SERVICES CAN BE BETTER CONTAINED  
ADULTS OR CHILDREN LIVING IN A DDSN RESIDENTIAL HOME

Better Management

Quality management

Management; monitor quality of inventory of products needed to support consumers

Review system for savings

Monitor and adjust

Look outside the box to review state contracts

Purchase items/materials from a less expensive place, but can't because of contracts

Bulk purchase of food

Quality of products now being used

Too many meetings

Less paperwork; more service delivery

System needs to be more proactive in asking for help

Increase fundraising

Technology

Use technology (2)

Use automated data collection

Transportation

Map out errands, trips to save gas

Transportation to job can be expensive cost for supporting consumers

Transportation is a problem; may use smaller vehicles

Staff

Using certified nurses' aides for some services

Not overusing "most expensive" staff

Data collection vs. interaction (paperwork in general needs to be less)

Family Issues

Offer respite for families

Individual cost analysis to parent

Other

Medical care; don't perform unnecessary tests

Tough to do

Making better use of technology was identified by this group as a means to control costs, and transportation was also seen as an area where costs could be contained, by combining trips or by using smaller vehicles. Using “less expensive” staff to perform certain tasks was also seen as a cost-cutting measure, as were performing fewer – i.e., unnecessary – medical tests and doing an individual cost analysis for families. As one participant noted, however, controlling costs is “tough to do.”

On the topic of health care, stakeholders of adults or children living in residential settings identified the quality of health care providers, the choice of providers, and communicating with health care providers as the main issues when thinking about obtaining health care for themselves or a family member. Finding providers who accept Medicaid and the Medicaid reimbursement rate, together with adaptive equipment and the need for a specific type of care were also identified in this discussion.

A number of related issues were cited when participants were asked about their concerns or barriers to obtaining appropriate health care (see Table 12). There were a number of concerns expressed about health care in general; for example, a shortage of specialists, medical care turnover, the use of generic drugs to save money, concerns about the quality of care and the overall future of the health care system. There were also concerns expressed about specific types of care, particularly dental care, but also psychiatric services, mental health care, audiology, and specialty care.

The cost of care and paying for services were also viewed as potential barriers to receiving appropriate health care. Focus group members were worried about finding providers who accept Medicaid, the cost of services, and the cuts that are being made, as well as the complexity of the payment system.

TABLE 12  
CONCERNS/BARRIERS TO APPROPRIATE HEALTHCARE  
ADULTS OR CHILDREN LIVING IN A DDSN RESIDENTIAL HOME

Health Care - General

Future of health care  
Medical care turnover  
Specialist shortages  
Concern that generic prescriptions might be used to save money  
Generic medications  
Using emergency room for non-emergency care  
Emergency room wait time  
Aging consumers; will they have to go to a nursing home  
Consumers alone at hospital, which can affect care  
More intervention  
High quality care  
Advocate for health care needs

Specific Types of Health Care

Dental care (3)  
Audiology  
Behavioral services  
Dual diagnosis care  
Mental health care  
Physical therapy  
Psychiatric services  
Specialty care (e.g., neurology; speech; gastro-intestinal; Baclofen; pump)

Payment/Cost Issues

Providers who will accept the waiver fee/payment  
Complexity of payment system – Medicare/Medicaid  
Cost is high  
Medicaid cuts; care negatively affected  
Change from fee-for-service to HMO means some doctors don't participate  
Funding; which providers will take Medicaid

Provider Issues

Monopoly of competition among providers  
Faith based provider wants to offer services  
Choice of doctor  
BSP providers

Staff Issues

More nurses at homes get burned out  
Better communication between healthcare provider, DDSN staff and family  
Staff not knowledgeable about need for specialist; costs more money and hurts consumer

Other concerns included the lack of choice and lack of competition among providers, better communication between providers and families, and issues related to the quality of staff.

The final question addressed in the focus group of stakeholders of adults or children who live in residential facilities was what it would take to live more independently. As with many of the previous issues discussed, there was no single response or set of responses that dominated this discussion; rather these participants provided a range of features that would help consumers to live more independently (see Table 13).

The first set of responses were related to the residential setting and included such aspects as the safety of the house, its affordability, the nutrition provided, and the compatibility of housemates. Transitioning and the need for good transition planning were also cited, as were group planning, the need to consider independence vs. risk, and available supports.

A number of supports related to the individual consumer were identified in this process. Jobs, particularly jobs that were meaningful or that consumers enjoyed, were seen as important in promoting independence. More information about the various levels of independence and more individualized programs were also considered important in fostering independence, as was the ability to return to a less independent setting if needed.

Another important consideration in helping consumers to live more independently was the development of life skills. Several comments were made to the effect that staff should teach consumers to perform tasks, rather than doing things for them.

There were both positive and negative comments made about the role of staff in helping individuals to live more independently, but agreement that good assessments and identification of the individual's appropriate level of independence are needed. The role of the family and its involvement are another important component in the move to independence.

TABLE 13  
WHAT IT WOULD TAKE TO LIVE MORE INDEPENDENTLY -  
ADULTS OR CHILDREN LIVING IN A DDSN RESIDENTIAL HOME

Residential Issues

Transition between programs when consumer may not be ready  
More support for Community Training Home 1 program  
Consumers should be able to pick housemates  
Affordable housing  
Safety  
Ensure money, nutrition, and vulnerability are monitored in more independent settings  
Understanding the risk of more independent settings  
Independence vs. risk  
Good transition planning  
Group planning

Consumer Issues

Consumers need good jobs they enjoy  
Meaningful jobs  
Jobs to enhance independence  
Willingness to be able to return to less independent setting if needed  
More individualized programs  
Less supervised time  
Need more information about various levels of independence; what the criteria are

Life Skills

Staff to teach, not just do things for consumers (3)  
Teaching daily living skills in home  
Training in homes to teach more independence  
DDSN needs to promote independence

Staff - Positive

Wonderful staff  
Great sign that staff stay for 20 or more years

Staff - Negative

Train staff in decision making for acceptable level of “risk”  
Red tape and paperwork that staff must deal with

Level of Care

Level of care that meets that person’s needs  
Good needs assessments  
Recognize some consumers cannot be independent  
Acknowledge “individual” independence level

TABLE 13

- cont. -

Family Issues

Families need better information about living options

Increase family involvement

Families are happy with level of independence

Other

Technology

Adaptive devices

Funding and communication

Fewer restrictions

## **Adults Living with Families**

The final focus group consisted of stakeholders of adults living with families. The information displayed in Table 14 indicates that virtually any support that DDSN provides was mentioned as important in reaction to the question of the supports that are most important.

Services – individualized services; quality services; day services; speech therapy; dental services; choice of services. Respite care – respite weekend; respite after hours; respite nursing; Mommy’s morning out; quality respite care. Quality of life – socialization; life skills; cognitive skills; activities of daily living; goal setting; safety. Supplies and equipment – incontinence supplies; feeding tubes and bags; a roll-in shower; a voucher system for supplies. Care issues – caregivers helping with activities of daily living; needs for therapy; overnight care; community resources for care. Paying for services – Medicaid resource limit; out-of-pocket expenses; difficulties in paying for services. Family issues – families needing information; families being responsible; families needing services; family support groups. Staff – quality staff; knowledgeable staff; patient-to-staff ratio; low wages for staff. Communication – the need for more information; information about services; communication across counties; information on transitions. Transportation – to social activities; to church; transportation too complex to use; transportation policy. Residential – options; placements; choice of locations; quality. Activities – day programs; field trips; summer camps; outside activities. Jobs - employment opportunities; job coaches; follow-up on jobs. Waivers – day waiver waiting list; waiver regulations; lack of movement on waiting lists. Service providers. Community supports. All of these items and more were referenced during the discussion of this question. The conclusion is that for adults living with families, virtually every support can be considered important. There is no one overriding need that stakeholders in this situation consider to be "most important"; rather any support available in the system is important and is utilized.

TABLE 14  
 MOST IMPORTANT SUPPORTS  
 ADULTS LIVING WITH FAMILIES

Services

Individualized services (2)  
 Customized  
 Quality of service  
 Day services; longer hours  
 Day supports  
 Day service supports should have higher rates  
 Speech therapy  
 Literacy/speech; specialized communication  
 Need for support for people with disabilities  
 Need more supervision  
 More monitoring  
 More training focused  
 Allow choice  
 Needs do not change because of a birthday  
 Evaluate results needed from services  
 Supports for individuals with high medical needs  
 Available placements  
 Appeals of services  
 Services need funding  
 Dental  
 Need consistency among agencies for services  
 Caps on services, so need to determine need  
 People are different; team approach to assess

Supplies/Equipment

Incontinent supplies going down in quality (2)  
 Underpants, wipes – using twice as much  
 Need to buy our own incontinent supplies  
 Supplies  
 Supplies come at different times  
 Feeding tube bags – high prices  
 Overpriced supplies  
 Need to order only what we need  
 Voucher system for supplies  
 Build up credit for quality supplies  
 Supply chain management  
 Shipping inefficient  
 Need roll-in shower

Respite Care

Respite (4)  
 Respite weekend  
 Respite for people who have no service  
 Respite nursing  
 After hours respite  
 Respite care center for a day or weekend  
 Residential respite program  
 Respite skilled care out  
 Need for dependable, responsive respite care  
 Need overnight place for care while away  
 Overnight and evening respite  
 Mother's morning out  
 Need more respite – never enough  
 Attendant care  
 Need help finding respite caregivers  
 Anti-burnout relief  
 Respite needs to be higher quality

Quality of Life

Socialization (4)  
 Learn to do life skills  
 Cognitive skills  
 More independent living training  
 Teach new skills  
 Want training to build skills  
 Sensory stimulation  
 Safety  
 Daily life activities  
 Goal setting  
 Person has goals  
 Learning independence in day program  
 Helping individuals  
 Companion  
 Familiar faces  
 Teaching needs to be ongoing  
 Peer support; "village" approach

TABLE 14

- cont. -

Care Issues

Caregivers – help with daily living activities  
Needs therapy  
Overnight/weekend care  
Need in-home overnight care  
Supervision while caregiver in hospital  
Some people need nurses available  
Attendant care; personal care aides  
Some require more than voc rehab can offer  
Seek other caregivers, like churches  
Connections to local groups  
Go into communities to create opportunities  
Try to use schools for services  
More volunteer opportunities  
Take time to understand  
Good documentation

Family Issues

Families may not be getting enough services  
Families need to know what to expect  
Families have to be responsible  
Work together with other parents  
Siblings may be able to help  
Parent support groups are helpful  
Equity; single parents may need more  
Caps on home modifications too low  
Need modifications to add room to home  
Pay family members  
Need live-in guardians  
Have open discussions about what is needed

Communication

Need more information  
More resources information for families  
Need more information about services  
More and better communication across counties  
Lack of information on transition  
Written information to aging caregivers  
Educate business community about abilities  
Other agencies give incorrect information  
Did not know about tonight's meeting

Paying for Services

Cannot stay on fee for service plan  
Hard to pay all expenses; food, healthcare  
What are the costs involved?  
Out-of-pocket expenses are going up  
Nurses cost more; waste of money  
Medicaid resource limit  
Long-term care insurance may not work  
Less Medicaid service due to age  
Single-source health; which is paying first?  
Flexible spending for services, supplies  
Voucher system for services  
Transportation provided for parents

Staff

Quality staff  
Knowledgeable service coordinator  
Concerned, caring staff  
Best practice training for staff  
Creative scheduling of staff  
Cross-train to help parents and consumers  
Prepare staff to take care of child  
Ratio of individuals to staff  
Low wages for direct support staff  
Need better pay for staff  
Need quality case managers  
Prevent staff burnout

Transportation

Transportation (3)  
Transportation to social activities  
Transportation to church  
Contract directly with local drivers  
Transportation too complex to use  
Changes/assistance in vehicle modification  
Change in new transportation policy  
Driver training for consumers

TABLE 14

- cont. -

Residential

Residential options close to family  
Want a residential placement  
Choice of location and provider  
Quality more important than size  
Need personal care aide to stay at home  
Out-of-home quality residential placement  
Parent/family wants to be part of transition  
Transitioning out of the home  
Preserve current living situation after caregivers

Jobs/Job Training

More employment opportunities  
Need more jobs  
Employment – focus on transition  
Need long-term job coach  
Job coaches  
Need follow-up on employment

Funding

Family support funding (2)  
Need more funding  
Therapies not being funded enough

Service Providers

More qualified providers  
Need educational class

Activities

Good quality day program  
Day programs  
Day program essential  
Day programs allow parents to work  
Field trips  
Summer camps  
Workshops  
More activities outside of program

Waivers

Waivers  
Address day waiver waiting list  
Waiver regulations get in the way  
Caps and cuts in waivers  
Need a waiver for qualified provider  
Diversity of day programs waivers

Waiting Lists

Day program waiting list  
No movement on waiting lists

Other

Community supports  
User friendly telephone systems  
Have place to go in emergency situations  
Need plan in place for emergency  
Ability to contact live staff  
Share day supports that go beyond respite  
Look at other states  
Volunteers work too

This conclusion is reinforced by responses to the question on the supports that are least important. In contrast to the numerous supports cited as most important, only a few – such as pay for work, provided lunch, an annual plan, and personal care attendants – were mentioned as least important. Stakeholders of adults living with families believe that the supports that DDSN provides are important and are reluctant to say that any of them are not necessary.

This group also believes that a number of aspects of the current support system are working well including the consistent service provided by the staff, the innovative approaches DDSN employs, and its focus on the consumer.

Although these stakeholders perceive these various features of the system to be working well, they also offered a variety of suggestions for things that DDSN can do to create or improve supports for individuals (see Table 15). The most frequent response to this question involved some type of service, including respite care, adult day care, behavior intervention, personal care, and rehabilitation supports. A second frequently mentioned set of responses involved service coordination, including reducing the service coordinators' caseload, providing them with better information, and providing them with more funding.

These stakeholders of adults living with families also identified a number of provider-related issues as a means for DDSN to create or improve supports to individuals. Among the suggestions were more providers, competition among providers, developing more quality providers, and providing more choice among providers. Dealing with Medicaid issues was another way in which DDSN could improve supports, particularly getting more practitioners to accept Medicaid, getting Medicaid coverage for additional services, and producing an updated list of Medicaid providers.

TABLE 15  
WHAT DDSN CAN DO TO CREATE OR IMPROVE SUPPORTS TO INDIVIDUALS -  
ADULTS LIVING WITH FAMILIES

Services

Behavior intervention  
More respite  
Week-end away respite in home  
Need to increase supports when there is a crisis  
Adult daycare  
Rehabilitation supports  
Personal care  
Attended care  
Develop more caregivers  
Develop more support for high functioning adults  
Maximize direct services  
Therapies do not work for adults  
Better transition from home to residential  
People in residential placement get more services

Providers

More providers  
Competition among providers  
Developing quality providers  
More choice of providers  
Transition from pediatric to adult providers  
Marketing plan needed to recruit more providers  
Too complicated to become a provider

Organization

Minimize administration  
Policies and procedures need to be simplified  
Interaction between staff and consumer

Jobs/Employment

More job coach development  
Better job coach to consumer ratio  
Need contract work

Health Care

Need link to health care system  
Children have greater access to health care

Service Coordination

Coordinator caseload too high  
Coordinators need better information  
Coordinators need to initiate contacts  
Coordinator should do case management  
Coordinator should coordinate all services  
Coordinator for special age groups  
Coordinators need better tools/information  
Level 2 coordinators should be funded  
Coordinator needs to advocate for Medicaid

Medicaid/Medicare

Finding practitioners who accept Medicaid  
Get more practitioners to accept Medicaid  
Medicaid dental care for adults is needed  
Medicaid vision care needed for adults  
Need updated lists of Medicaid providers  
Medicaid has too many limitations

Funding

More funding for services  
Funding to develop residential options  
State needs to fund more services  
More funds for respite  
More advocacy to policy makers  
Some states doing much better in funding

Communication

Sharing information  
Need an updated list of companions  
Newsletters

Quality of Life

Need healthier lifestyle  
More activities for people on waiting lists  
Need socialization for consumers

Transportation

Transportation a big need  
Transportation  
Some people need transportation

Obtaining more funding for services – to develop residential options, for respite, and the like – was also cited as a way for DDSN to create or improve supports for individuals. Other ways identified by this group as ways for DDSN to create or improve supports for individuals included more efficient organization; better communication and sharing of information; more jobs and better job coaching; more activities; an improved link to the health care system; and better transportation.

While there is some overlap between the responses for how DDSN can create or improve supports for individuals and how it can improve the value of supports for consumers and families, there were differences in emphasis of these responses (see Table 16). In discussing supports for consumers and families, this group cited the need for more funding, specifically in areas such as scholarships, personal supports, and durable medical equipment. Concerns about staff were also more frequently mentioned in response to this question, including more training for staff, training staff to work with people with disabilities, and paying staff more in an effort to reduce staff turnover.

This group also identified several issues related to supplies, particularly incontinence supplies, and believed that more information, better training, and more face-to-face family meetings would improve the value of supports for consumers and families. Stakeholders also expressed a desire for more services focused on the consumer, for more jobs, for more activities for consumers, and for improved transportation. Communication was also seen as important in improving the value of supports for consumers and families.

These stakeholders did not offer many suggestions for containing the cost of services. Among the suggestions considered were more fuel-efficient routes, getting volunteers to provide services, such as minor repairs, and getting more outside support from the community.

TABLE 16  
WHAT DDSN CAN DO TO IMPROVE THE VALUE OF SUPPORTS FOR CONSUMERS  
AND FAMILIES - ADULTS LIVING WITH FAMILIES

Funding

More funding  
Need more funding, not cuts  
Scholarships  
Parents have to beg for funds every year  
Spend funding on personal supports  
Spend durable medical equipment money wisely

Equipment/Supplies

Problems with incontinence supplies  
Incontinence supplies are inadequate  
Waste supplies that do not work  
If cost of products are same, let family choose  
Transparency on inventory

Services

Consumers first; provide the best  
Provide quality services through smaller groups  
Ask the crucial questions for better screening  
Involve local churches with programs  
Plan development and implementation

Communication

Communication  
Communication of progress  
Counterpart meetings

Service Coordination

More home visits for service coordinators  
Better informed service coordinators

Staff

Continuous on-the-job training for staff  
Training specific to people with disabilities  
Less staff time doing paperwork  
Volunteers to assist with staff  
Pay staff better to prevent turnover

Family Issues

Better information for siblings new to role  
Prevention of siblings as sole caregivers  
Training parents in grass roots policy  
Family face-to-face meetings

Employment/Jobs

Competitive employment  
No more excuses – jobs are out there  
Work program

Activities

Day programs need to be productive  
Groups in day program with same interests

Transportation

Look at a van route  
Ask for fuel cost for families

Other

Stop misuse of public programs  
Movement on waiting list  
Consider temporary Medicaid support  
Informal process of resolving issues  
Shift burden of no-shows to home health  
Leadership provider's level

When the group discussion focused on health care, these stakeholders identified a number of concerns related to obtaining care for themselves or a family member (see Table 17). The thing that came to mind for several of these participants involved the availability of doctors. The general availability of doctors, locating doctors in rural areas, finding specialists, and the need for more choice of doctors were mentioned. Access to dental services was a particular concern of this group.

Stakeholders were also concerned about paying for health care. Identifying practitioners who accept Medicaid, the range of services that Medicaid covers, and the level of reimbursement were mentioned in this regard.

Communication about health care was also seen as important to this group, particularly access to information about available services and medical resources, a directory of medical professionals, and information on the quality of services. Several concerns about waiting lists were expressed during this discussion of health care, including the perception that they were too long, that there was little movement, and that families need more information about waiting lists.

Among the other concerns that stakeholders of adults living with families identified as concerns related to health care for themselves or a family member were the need for doctors who are knowledgeable about treating people with disabilities but also willing to listen to families in treating these consumers; locating and obtaining appropriate medical services, including respite care, long-term care, catastrophic care, and behavior supports; and the quality of available services.

The final discussion point for the group of stakeholders for adults living with families addressed the supports needed to continue to provide care in the home. As with several of the previous questions considered by this group, a variety of supports were identified (see Table 18).

TABLE 17  
WHAT COMES TO MIND WHEN THINKING ABOUT HEALTH CARE FOR YOURSELF  
OR FAMILY MEMBER - ADULTS LIVING WITH FAMILIES

Availability of Doctors

Not enough doctors  
Keep doctors in South Carolina  
Specialists limited in rural areas  
Eye doctor  
Limited access to vision services  
Ability to choose doctor  
Continuity of doctor is important  
Need more choice of providers

Communication

Need directory of medical professionals  
Need to know what services are available  
Medicaid provider contact information inaccurate  
Make it easier to identify medical resources  
Need an "Angie's list" for free  
Medicaid vs. Medicare information confusing

Knowledgeable Doctors

Need providers knowledgeable about disabilities  
Better education for providers about disability  
Push medical schools to educate about disabilities  
Medical professionals need to listen to families  
Doctors need to understand parents are experts

Medical Services

Locating proper medical services  
Expand role of nurse practitioners  
Respite relief during consumer hospitalization  
Need more group homes  
Durable medical supplies need to meet needs  
Long-term or lifelong care services  
Catastrophic care services  
Good behavior supports  
Can house be funded for live-in help  
Accessing doctor sitter service

Payment

Need practitioners who accept Medicaid (2)  
Need dermatologists who accept Medicaid  
Medicaid does not cover enough  
Reimbursement not high enough  
Co-payments

Dental Service

Limited access to dental services (2)  
Dental  
Need money for dental services  
Have to go out of town for dental problems  
Dental access at school is good for children

Waiting Lists

Waiting lists  
Waiver waiting list too long  
Transition from school waiting lists  
Inform families to get waiting lists

Supplies

Quality incontinence supplies limited  
Reduced supplies reduced cost more later

Quality of Services

Primary care services are adequate  
Dental and vision therapies are lacking

Other

Cost of medication (2)  
Transportation barriers  
Share medical record information  
Doctors send to the emergency room  
Close down or use regional centers  
Inappropriately made Medicaid ineligible  
DDSN paying for people from Corrections

TABLE 18  
SUPPORTS NEEDED TO CONTINUE CARE IN YOUR HOME -  
ADULTS LIVING WITH FAMILIES

Services

After hours care (2)  
Day services  
More day supports  
Increase day program activity  
Expand day program  
More money for day programs  
Transition planning important  
There has to be something to transition to  
Transition plan in case of emergency  
Temporary plan for crisis situations  
Need short-term out-of-home emergency care  
Have preparations made for emergencies  
Improve person-centered services  
More focus on the individual  
Plans tailored to the individual  
Individual needs need to be communicated with  
More qualified providers  
Rehabilitation support  
24-hour support  
Equal access to services  
Service to be entitlement

Caregiver Support

Increase caregiver relief programs  
Homemaker services for family caregivers  
Respite care  
Crisis home respite  
Personal care aide - respite care  
Personal care aide - attachment care  
Caregiver support  
Yard care

Staff

Staff doing great job, even with less funds  
More sign language skills of staff  
Maintain current hiring process  
Pay family as staff

Residential

Appropriate residential placement  
Support individual in his or her home  
Combine resources to create a home  
Continue residential options  
Consumer created services house  
Increase local options  
Choices  
Place like people together  
Peer housemates  
Emergency residential home placement

Family Issues

Ability of parents to choose  
Personalize and meet parents' standards  
Assurance of what will happen to loved one  
Improve education about respite care  
Connect providers with families  
Families must be able to work  
Family ad hoc units  
Community involvement after parents gone  
A home in county close to other family

Communication

Be told about available services  
Constant communication  
Communication a continual process  
More contact with leaders  
Boards should have list of companions

Other

Technology to help  
Movement on waiting list  
More funding needed  
Lifts; ramps; bathrooms  
Flexibility of money to meet needs  
Advisory Board  
Volunteers  
Friends

And as was the case with several of these previous responses, there was no single support or service that was identified repeatedly, but rather a wide range of elements were mentioned.

The largest number of these responses was related to services. These included features such as after-hours care, day services, program activities, emergency or temporary services, and rehabilitation support, and several of these comments cited the need for transition planning and a focus on the needs of the individual as part of the services provided.

A related set of comments addressed residential issues, including the supports an individual receives in the home, providing an appropriate residential placement, putting similar individuals together in a home, and increasing the range of available residential options.

Family-related issues were also an important consideration in continuing to provide care in the home. Features such as individualized programs, connecting families with providers, improving respite care, and being close to other family members were cited in this discussion.

Caregiver support was also frequently mentioned as important in continuing to provide care in the home. Features such as respite care, homemaker services, personal care aides, and yard care each contribute to the ability to continue to provide care at home.

This group also identified communication as important to the ability to provide care at home. Keeping people informed about available services, making available a list of providers, and continued communication were discussed in this session.

Other topics mentioned in response to this question were related to the quality of staff support, the use of technology, and the use of volunteers or friends to provide assistance.

### **Stakeholders Online Survey Results**

The final component of this project was the online survey of stakeholders. As noted previously, 286 people completed at least part of this survey, which addressed many of the same

issues as those considered in the focus groups. Table 19 provides several of the characteristics of the respondents to this survey. As this information shows, respondents to the online survey represented not only those included in the focus groups but other stakeholders, such as DDSN employees or individuals with an interest in the DDSN system. This analysis concentrates on those groups for which focus group information has been provided. While the results of the online survey support the conclusions of the focus groups, there are several differences that should be noted.

*Families with Children Birth to Age Five at Home.* Online respondents with children ages birth to age five at home more frequently mentioned Pervasive Developmental Disorders, Applied Behavior Analysis, and service coordination as supports that were important to them than did participants in the focus group. Online respondents identified fewer aspects of the current support system that were working well than were mentioned in the focus group.

In terms of ways in which DDSN can improve the supports for children and families, the responses from those who completed the online survey were more concentrated in the areas of providing qualified staff and service, expanding services, and getting off of the waiting list for services. The cost and quality of care were among the main items that people mentioned in terms of health care. Survey respondents cited the need for family involvement, transportation, and the ability to attend regular classes as important supports in the transition to school.

*Families with School Age Children, Ages Six to Twenty Years.* Among the supports most frequently mentioned as important by online survey respondents in families with school age children ages six to twenty were respite care, personal care assistants, the Pervasive Developmental Disorder waiver, and community supports. Survey respondents were more likely than focus group participants to name a service that was least important. While services such as vehicle

TABLE 19  
CHARACTERISTICS OF ONLINE SURVEY RESPONDENTS

<u>Relationship to DDSN</u>	<u>N</u>	<u>%</u>
Adult family member who receives services from DDSN	71	24.9
Qualified provider in the DDSN service delivery system	54	18.9
Child between the ages of 6 and 20 receives services from DDSN	45	15.8
A person interested in the DDSN system	35	12.3
DDSN employee	34	11.9
Family member on a waiting list	20	7.0
Child under the age of 6 receives services from DDSN	17	6.0
Receives services from DDSN	9	3.2
<u>Living Situation</u>		
Family member is at least 21 and lives at home with family	45	37.2
Family member age 6 to 20 lives at home with family	44	36.4
Family member is at least 21 and lives in a residential setting	21	17.4
Age 21 or older and lives at home with family	5	4.1
Family member in a residential facility not operated by DDSN	2	1.7
Family member under 21 and lives at home with family	1	0.8
At least 21 and lives in own home either alone or with a roommate	1	0.8
Family member under 21 and lives in a DDSN residential setting	1	0.8
Family member at least 21 - lives either alone or with a roommate	1	0.8

accommodations, case management, residential care, diapers and waivers were mentioned as “least important” supports, the tone of these responses was not that these services were not important overall, but more that they were not applicable to their particular situation at the present time. As with the focus groups, a number of respondents indicated that all services were important.

Respondents in families with school age children ages six to twenty generally believed that service coordination and the Pervasive Developmental Disorder waiver are current supports that are working well.

The main themes for creating or improving supports identified by stakeholders with children in the six to twenty age range during the focus group were information and communication, cost-related supports, and access. In the survey, the most frequent suggestions for creating or improving supports were to focus more on providing individualized care, providing more respite care, and stop cutting services.

Survey responses on the issue of health care largely mirrored those of the focus group, with respondents citing features of the health care system such as the cost of services, the services Medicaid does not cover, finding providers who accept Medicaid, finding quality service providers and cuts in spending as concerns. The health care bureaucracy was also mentioned as a barrier to receiving appropriate health care.

The important considerations in transferring out of the school environment cited by survey respondents were also similar to those identified in the focus group. Job related supports, job training, and job choices were mentioned, along with the needs for skills training, an appropriate placement, and community supports.

*Adults or Children Who Live in Residential Settings.* The number of supports identified by survey respondents with adults or children who live in residential settings was not nearly as

extensive as the number mentioned in the focus group, but they did touch on many of the same issues. Among the most important supports mentioned in the survey were quality of life issues, such as safety and a clean living environment; quality of staff; supervision; living supports; social supports; transportation; and medical needs. While many survey respondents indicated that all supports were important, several supports, including workshops, the annual support plan, and 24 hour "awake" staff were considered least important.

The features of the current support system that are working well identified in the survey were similar to those mentioned in the focus group. Residential teams and a clean, well-maintained home, the quality of the staff, the activities and programs available, and service coordination were among the elements of the current system that were reported to be working well.

As reported in Table 9, stakeholders of adults or children who live in residential settings had an extensive number of suggestions for things that DDSN could do to improve the value of supports to individuals. The suggestions for improvements from survey respondents were more focused on issues such as staff training and behavioral training, reducing staff turnover, better pay for staff, and having more job opportunities.

As in the focus group, survey respondents cited the costs of health care and identifying providers who accept Medicaid as health care concerns. A number of respondents felt that it would not be possible for their family member to live more independently. Those who believed greater independence was possible thought that the development of life skills and additional therapy, such as physical or occupational therapy, would be important in any move toward independence.

*Adults Living with Families.* Like their focus group counterparts, survey respondents with adults living with families mentioned a number of supports as most important, although their responses were more concentrated in the areas of respite services, day programs, workshops, and

rehabilitation supports. This group of respondents believed that many of the current supports work well, particularly service coordination, case management, and day programs, and thought that these supports could be improved by increasing the continuity in service provision, providing more employment opportunities, providing more individual or personalized attention, and reducing waiting lists.

As with survey respondents in other groups, those with adults living at home identified costs and finding quality providers as main health concerns. Supports most frequently mentioned as needed for continuing to provide care at home included day programs and respite care and, to a lesser extent, a greater choice of providers and making provisions or planning for long-term care.

### **Summary**

The previous sections have reported an extensive amount of information collected as part of these focus groups and the online survey. This summary attempts to synthesize this information and the implications for the services that DDSN provides.

DDSN serves a diverse set of clients. There is no consensus among these clients about the positives or negatives in the DDSN system. Assessments of DDSN are dependent upon, among other factors, the severity of the disability with which they are faced, where they are in the life cycle, and the resources and supports they have available to them as families. Despite this diversity of responses, however, there are several general conclusions that can be drawn.

(1) Virtually every service that DDSN provides is considered important by consumers. This is evidenced most vividly in the responses of the focus group for adults living at home during which an extensive range of services were described as “most important,” but it is evident in the other groups as well. Stakeholders need the services and supports that DDSN provides and they consider them to be important. While the identification of the “most important” service

varies across groups, respite care, quality staff, and service coordination are generally considered important. Important supports for different groups vary by circumstances. Early intervention therapies are more important to those with children birth to age five, while personal care aides are mentioned more frequently by those with children ages six to twenty, respite care is more often needed by families with adults living at home, and quality of life measures and compatibility with other residents are more important to stakeholders with a family member in a DDSN residential facility.

(2) There are virtually no supports that are considered to be “least important.” Although several individual services were mentioned as part of these groups or in the survey, the sentiment clearly expressed was that “all services are important.” The one support that was mentioned most frequently as least important was the annual life plan.

(3) Stakeholders generally believe that the DDSN system works well. Aspects of this system that were perceived to be working well varied by living situation. Those with children from birth to age five felt that Pervasive Developmental Disorders waivers and service coordination worked well; those with school-age children ages six to twenty cited waivers and family supports; those with adults living at home identified the consumer focus and consistent services as features that worked well; and those with a family member in a residential facility cited features of the home, such as cleanliness or safety, as well as the quality of care provided.

(4) The most frequently identified ways in which DDSN could improve the supports it provides were training of staff, continuity of care, assuring the quality of services, and providing additional funding.

(5) Stakeholders offered a number of suggestions for containing costs. Many of these were general suggestions such as to use best management practices or to monitor costs. Specific

suggestions included using more technology, using more fuel efficient vehicles and combining trips, and using more volunteers to provide services.

(6) Health care concerns consistently identified included the need for more providers who accept Medicaid; more services that would be covered by Medicaid; the need for more providers; the need for more specialists; and more choice in providers. Concerns about dental care were also expressed across groups.

(7) Throughout these groups, participants expressed the importance of communication. Communication about available services, communication with physicians, communication between family members and DDSN staff, and between DDSN and the community were among the types of communications mentioned as important.

(8) Although the value of and need for communication was expressed in a number of the items considered, it was particularly important in transition planning. Stakeholders wanted to know the types of services that were available. The need for planning for any transition, as well as the need for service coordination throughout the process, were considered important.

The diverse set of consumers served by DDSN values the supports they receive and generally feels that the system is working well. They are concerned about change and about health care, and they value quality, consistency, and continuity in the services they receive. Information and communication with DDSN are important to them in making decisions that contribute to their quality of life.