

In addition to the input from the Individual and Provider surveys conducted by MarketResponse International, visits were scheduled in eight regions of the state to talk with people with developmental disabilities, families, advocates, program managers, and front line staff. The purpose of these meetings was to listen to the people who are receiving and providing services, to learn about the issues that are important to them, and to gather their ideas and suggestions on where and how services and supports could be improved.

The notes taken during these meetings and interviews – the qualitative statements – were then organized into categories. This input and the personal quotes are intended to supplement the quantitative results that are presented in the report prepared by MarketResponse International.

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## **1. COMMUNITY**

- We receive great community support.
- Beverly and Arthur (both have disabilities) live next door to retired bankers. They visit and have coffee together. One day, Beverly and Arthur cleaned out their closets and presented their neighbors with a bag of clothes. The bankers promised they would each select one item and then pass on the other donations.
- People in the community need to realize that you can contribute if you have a disability.

## **2. COMPLEXITY OF SYSTEM**

- There are at least 40 items on our staff training list.
- Documentation has increased. There is more scrutiny than ever.
- The annual has 13 signatures on the form.
- Why do DHS and the Department of Health both license IFCs/MR? It is duplicative.
- The Department of Health is requiring programming in 13 different Activities of Daily Living. Why? It is too much.
- Drivers age 16 – 18 are too young to drive residents. Drivers over age 65 are too old and must have a doctor's signature to drive residents. Why?
- The system is becoming increasingly impersonal.
- The system is overwhelmed and overwhelming.
- The system is becoming more restrictive; consequently, consumers are becoming less independent.
- The people making the decisions "don't have a clue" about the developmental disabilities field.
- Broad decisions are made to encompass everyone's interests rather than the interests of individuals.
- There's more focus on quantity, not quality.

## **2. COMPLEXITY OF SYSTEM, cont'd.**

- There are too many requirements/regulations and not enough funding to follow through.
- System accountability and enforcement are down. No one knows any answers. No one knows the history of our field.

## **3. CONSUMER**

### **a. Choices**

- The term “consumer choice” is a façade. Other states have more consumer choice and better monitoring.
- Our agency is much more client focused.
- The only right is to wait for a waiver.
- I recently moved but I did not see the house before I moved. Everything is picked out for me (provider, staff, people I live with).
- Choice means staff choice.
- Too many staff have “control” issues.
- Residential staff prevent individuals from voicing opinions.
- People have the choices of likes and dislikes.
- When money is tight, it's no longer consumer choice; it is county choice.

## **3. CONSUMER**

### **b. Needs and funding**

- Clients have no money. A \$91.00 personal needs allowance does not cover copays or People First costs. Medicare Part D – good luck.
- People can cycle through mental health issues, medical issues, and behavior issues. Their lives aren't straight lines, but funding is.
- Copays eat up a personal needs allowance.
- Eliminate co-pays.

**3. CONSUMER**  
**b. Needs and funding, cont'd.**

- As clients age, they have more disabilities; their bodies are breaking down. Funding does not match needs.
- Eliminate the funding cuts that affect people with disabilities.
- No additional funds are available as consumer needs change.
- Assistive technology is available, but not to all consumers because of cost.

**3. CONSUMER**  
**c. Self advocacy**

- Without self advocacy, the State of Minnesota would run our lives.
- Let's get self advocacy into high schools.
- In the past three years, self advocates stopped complaining and started doing a community service project each month.
- Our most important work is coordinating self advocacy.
- I run my own team meetings.
- I want goals. I don't want programs.
- People with developmental disabilities are losing self advocacy opportunities because staff are saying, "It's too much work."
- Staff are untrained about self advocacy.
- Self advocacy –
  - It's hard to find coordinators who are energetic, compassionate, and who get it.
  - The Arcs should coordinate People First rather than providers.
  - The vision is for at least one People First chapter per county.

#### **4. COUNTIES**

- There is inconsistency in county requirements, and lack of uniformity across counties about expectations and requirements.
- There are inconsistencies among counties regarding referrals, RFPs, and contracts. There is no level playing field.
- We are no longer on the same side. Counties are on the opposite side.
- We get calls from elderly parents and grandparents but they refuse to go to the county for help because of stigma.
- Rural counties are getting short changed. This increases the disparity between rural and metro areas.
- I want a social worker who will listen to me and not sell me short.
- In one group, half said their social workers responded to their calls and half of the social workers did not respond to calls.
- Case managers visit clients regularly.
- Counties need a primer on developmental disability services, as do families.
- Case management is personality based.
- Case loads are too big for case managers to get to know the people for whom they are making decisions.
- Find more case managers and/or public guardians to lower the case load and increase involvement.

#### **5. DATA PRACTICES**

- Data practices have become the new way to dehumanize someone, to take away their name, their right to be in a newspaper, their right to have visitors in the hospital, their right to receive mail, and their right to share news about death.

**6. DAY PROGRAMS**  
**a. Businesses**

- Businesses call us for workers.
- People are open to hiring. Stereotypes have been broken.
- “Place and train” versus “train and place.” Businesses want skills.
- We are successfully getting jobs. We have versatile work.
- Every person can select his/her own job.

**6. DAY PROGRAMS**  
**b. Funding**

- Some counties are refusing to pay for anyone referred for employment services.
- Why doesn't Rehabilitation Services voucher funds directly to consumers and get away from the rehab counselor model?
- Client needs are changing. We don't have enough staff to take care of personal needs and also do programs. We need a 1:4 ratio, not a 1:10 ratio.
- Every individual should be earning minimum wage.
- We need more funding.
- We need more funding for computers.
- There aren't enough choices during the day. We need more community inclusion.

**6. DAY PROGRAMS**  
**c. Changes in the nature of jobs**

- Entry level, low skilled jobs are going away. We need workers with disabilities who can multi-task and possess computer skills.
- Our local college has accepted a student with severe disabilities into a welding course.

## **6. DAY PROGRAMS**

### **c. Changes in the nature of jobs, cont'd.**

- Our local college has accepted a student with severe disabilities into a chef course.
- Mike was hired to clean at a casino but instead he stood at the door and stopped people as they were leaving. He would say to them, "You don't want to leave yet." Sort of a reverse Wal\*Mart job.

## **6. DAY PROGRAMS**

### **d. Residential problems**

- One client lost a week of work because the residential staff refused to get up and give a 5:00 a.m. medication.
- Clients are staying at home 24 hours a day. Residential staff are not providing support for community activities.

## **6. DAY PROGRAMS**

### **e. Other**

- Day programs have prevented the use of nursing homes.
- We need bigger buildings, bigger bathrooms, and bigger changing tables because more people are using wheelchairs.

## **7. FUNDING**

### **a. Overall**

- The legislature has only increased the Cost of Living Adjustment (COLA).
- Other costs have increased dramatically including workers compensation (70% increase), health care (15% increase), and unemployment compensation.
- Negotiations no longer occur with the county. We used to look at the individual and their needs, and negotiate funding. There is no cushion.
- Everything is financial. If there is one person who turns over in a 4- person home, then we must fill that vacancy ASAP.
- We are no longer care driven, we are driven by bill paying.



## **7. FUNDING**

### **a. Overall, cont'd.**

- We have a 1% margin. We cannot grow.
- There are only a few vendors in the nation selling liability insurance.
- We spend more money than other states, but our spending isn't rational. Some suburban families have to spend money just to get rid of it while there is no help for rural families.
- Providers are reaching maximum capacity.
- There are too many unfunded mandates.
- Increase reimbursements.

## **7. FUNDING**

### **b. Waiver**

- The waiver is a mess.
- People are beginning to ask questions about individual waiver allocations. How much money is being spent?
- Let's rename it the "Vulture Waiver." We sit around and wait for someone to die, and then pounce on their resources to get some help.
- Or something drastic has to happen – like going to jail; then you can collect a waiver.
- Benton County gets one waiver slot every other year. That's laughable.
- Emergency placement occurs only after all relatives have been considered.
- A lack of waivers mean waiting lists.
- All people should be entitled to services. There should be no waiting lists.
- It is unclear about who is deciding what services are available and how services are defined.
- There is no stability. Both services and funding are constantly changing.
- There is no money for growth.

## **7. FUNDING**

### **b. Waiver, cont'd.**

- The number of consumers increases but no new services are available.

## **8. HEALTH CARE**

- People with developmental disabilities are not getting needed medical evaluations because doctors are saying the clients have less quality of life, are less productive, and don't feel pain.
- Speech evaluations are turned down, CAT scans cancelled, and DNR/DNI demanded for every person. Medical staff talk to staff members but not the person.
- Dental care – we lost another dentist.
- Behaviorist – we have to pay if the behaviorist isn't an MA provider.
- We have to pay for all contacts with medical doctors at a rate of \$75/month. Phone calls used to be free.
- There are very few psychiatrists in our region.
- The local hospital will not handle crises. They tell us to take people elsewhere.
- Hospitals don't want to help our clients. They insist we provide staffing but that's double dipping.
- There are no copays in an ICF/MR. We are worried about Medicare Part D. We have one pharmacist to help 63 different people.
- The dental cap was lifted.
- Medicare Part D is insane. People with developmental disabilities cannot do it. Case managers have spent huge amounts of time and deserve credit for their work. Why should we get lumped in with the elderly? People are so used to having one white card for MA and now they have all kinds of cards. What is the theory?
- How can people have only one wheelchair in 5 years and only 5 repairs in a year?

- We help consumers to be safe and healthy.

## **8. HEALTH CARE, cont'd.**

- There is a lack of availability of local specialized health care, including psychiatrists, psychologists, dentists and other specialists.
- We need more dental services.
- Offer incentives for more professionals to become psychiatrists and psychologists.
- There is a lessened quality of care due to:
  - Lack of access to dental and health care;
  - Lack of new waivers;
  - HIPPA;
  - Limited psychiatric services;
  - Budgets – funding freeze;
  - Potential for injuries.

## **9. HOME OWNERSHIP**

- Why aren't parents being told to turn over their houses under a special needs trust? You can download the forms from the Internet.
- Professionals do not support home ownership for people with developmental disabilities. Professionals are keeping people impoverished.
- People with disabilities can't save for bigger purchases; there are too many asset limits.

## **10. LEGISLATION**

- Why pass any new laws? No one pays attention to the current laws?
- Educate our legislators.
- Invite our legislators to hear our concerns and ideas.
- Get out and vote.

- Write letters to legislators.
- Involve self advocates in presenting to legislators.
- We have the ability to “boot out” elected officials.

## **10. LEGISLATION, cont’d.**

- Our state is progressive but we’ve gone backwards in the past three years (i.e. parental fees).
- Our Day at the Capitol was successful because people with developmental disabilities testified in front of 12 legislators. They spoke from their hearts.
- Legislators are uninformed.
- Legislators are focusing less on humanity, and more on sports and arenas.
- Legislators are focused on tax cuts rather than services.
- Legislators should work in the field.

## **11. RESIDENTIAL**

### **a. Group Residential Housing**

- Minnesota does a good job in Group Residential Housing. Otherwise, people would live in tarpaper shacks.
- Not sure about the future of Group Residential Housing.

## **11. RESIDENTIAL**

### **b. SILS**

- Why not expand SILS? It’s a great program but has had no growth at all.
- It is LRE (least restrictive environment) and it is individualized.
- Some consumers have aged and need a rate adjustment for SILS. The last adjustment was ten years ago.
- Money for SILS programs runs out before the contract year ends.

- No one talks about referrals to SILS. No one talks about a waiting list for SILS.
- Counties have no interest in SILS.
- Why not fund more SILS services?

**11. RESIDENTIAL**  
**c. Waiver homes**

- Four pack homes are in lock down on weekends. If one person misbehaves, then no one can go places.

**11. RESIDENTIAL**  
**c. Waiver homes, cont'd.**

- Some homes have only one staff member all weekend. Is this a management issue or a funding issue?
- Even good providers can slip. This sign was on a door: "This is a private residence. No one can enter."
- There is variability in housing "quality."
- Lower your expectations of providers.
- There are excellent in-home programs that keep people in their own homes and private foster care.

**11. RESIDENTIAL**  
**d. Cash flow**

- We had one empty bed in our ICF/MR for eight months. The rates are the same but there are more behavior/medical needs for incoming residents.
- Rate adjustments last only one year.

**12. SAFETY**

- There is a mandate for safety but no money to match the mandate.
- It's taking too long to process and resolve maltreatment reports.

**13. STAFFING**  
**a. Recognition**

- There is lack of recognition for choosing this field.
- Direct care is not seen as a career.

**13. STAFFING**  
**b. Wages**

- Starting wages for direct care staff is \$7.50.
- We need better pay.
- The salary is too low for the responsibilities that direct care staff have.
- Some staff work three different jobs.
- Wage enhancements don't meet the cost of living.

**13. STAFFING**  
**c. Turnover**

- Staffing is our biggest problem - turnover every six months, turmoil, discontinuity for clients, burnout, and low compensation.
- No one challenges staff; otherwise there will be turnover. Providers don't want turnover.
- How do we address burnout?

**13. STAFFING**  
**d. Responsibilities**

- Responsibilities have increased. We expect people to be sharp and to make judgment calls, but we don't pay them.
- The staff don't have their own checking accounts but they have to balance checkbooks for clients.
- Staff received inadequate pay for the number of physical transfers. The staff stay because of the variety of tasks.

- Staff responsibilities are far greater than the wages received.
- Staff are overloaded with paperwork.

#### **14. TRAINING**

- We have huge training needs. Maybe 25% of the providers get it. Administrators don't know how bad things are. It's "hear no evil, see no evil."
- Hold community forums.
- Educate the community about developmental disabilities.
- Train support staff.
- Train consumers.
- Train educators about students with disabilities.
- Train bus drivers.
- More training programs.

#### **15. TRANSITION**

- Students don't have job skills.
- Transition – to the couch.
- Our local special education programs are great but not at transition.
- There are no funds for employment or residential services for students graduating from high school.
- Why isn't anyone enforcing transition requirements?
- Transition is a total disappointment. We were given no menu. No one knew about post secondary education. We have no program – he has Asperger's and his IQ is 120. The county has him in a mental health day program. Another parent is receiving no help. She asked, "What if I die?"
- Followup studies from high school would be helpful to provide feedback (what worked, what could be improved).

- Interagency Early Intervention Committees (IEICs) and Community Transition Interagency Committees (CTICs) can be effective especially in getting information out (special events). Schools ignore mandates so parents have to do all of the work.

## **16. TRANSPORTATION**

- “Transportation is not a problem unless you want to go somewhere.”
- Clients are making less money, transit costs are increasing, and some clients refuse to go to work because of bus fares.
- We have no accessible public transportation.
- We have a good transportation system. The local providers take people to medical appointments, counseling, jobs, recreation, anywhere.
- Our local community runs bus service from 6:00 a.m. to 10:00 p.m. It’s a terrific help.
- Fifteen passenger vans are not being built anymore so we will need three – 10 passenger vans rather than two – 15 passenger vans. There are extra costs but no one at the state seems to realize this. We aren’t receiving enough transportation funds.

## **17. WAITING LISTS**

- One mom is 72 years old, her son is a young adult, and they receive no help from their county.
- The counties say there is no money.
- The counties say there is a capacity problem rather than no funding.
- No new waivers cause hardships.