

Date

Dear Editor:

The Metropolitan Council has adopted a Regional Policy Plan for Persons with Developmental Disabilities. The focus of the plan is to promote quality services which lead to increased self-sufficiency for persons who are developmentally disabled and to their genuine integration as participating members of their communities.

To promote awareness and use of this plan, a member of the Council's Developmental Disabilities Advisory Committee will arrange to make a short presentation and provide a packet of written materials to your organization-The materials are suitable for publication in your newsletter. They include an executive summary of the plan and a series of original poems which illustrate some of the principles highlighted in the plan. The poems are based on the experiences of actual people who live in the Metropolitan Area.

Enclosed is a cover release, the executive summary and poetry. We recommend use of the cover release, and poem on the principle of community integration in the initial publication, followed by additional poems in subsequent issues. However, feel free to use the materials in the way that best meets your membership needs.

If you have any questions about the materials, please call Toni Lippert, Metropolitan Council, 291-6364.

Sincerely,

Mary Powell, Chair  
Development Disabilities Advisory Committee  
Metropolitan Council

MP:esw  
Enclosure

EW0073/HMHLH2

## A REGIONAL POLICY PLAN FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Four out of every 1,000 Twin Cities residents have severe, chronic physical or mental handicaps that began before age 22, and will probably continue throughout their lives.

These handicaps, called "developmental disabilities," interfere substantially with at least three basic living skills, such as self-care, learning, language development or mobility.

People with developmental disabilities tend to have several handicapping conditions that require combinations of service - family support, residential programs, education, training for employment, health treatment and therapy, and social and recreational programs. These services must address their multiple needs over the entire period they need assistance.

The Developmental Disabilities (DD) Program for the seven-county Metropolitan Area was established at the Metropolitan Council in 1972. The Council's Developmental Disabilities Advisory Committee oversees the DD Program and advises the Council on the needs of people with developmental disabilities.

The purpose of the program is to help develop a community service system that is comprehensive and enables persons with developmental disabilities to participate as fully as possible in the life of their own communities.

The Metropolitan Council adopted a new Regional Policy Plan in 1985 to promote a quality community service system. The plan contains advanced ideas about the kinds of services that should be delivered. It also includes appropriate goals the Metropolitan Council holds for its constituents who are developmentally disabled. These goals can be achieved if all individuals with an interest in their welfare will use the plan's guidelines and criteria to evaluate current services and practices. If the service system does not measure up to these standards, then the community at least has indicators of what changes are needed in all areas of the system.

### HOW TO USE THIS PLAN

The Metropolitan Council and its Developmental Disabilities Advisory Committee use these policies when they develop DD work plans or projects, and for reviewing other DD current or proposed projects, policies and practices. Consumer organizations, public and private policy-makers or service providers are encouraged to use it for long-range planning, for identifying individual needs, for evaluating or monitoring service systems and for creating positive change.

### WHAT THE PLAN CONTAINS

The plan starts with a description of a model array of services heeded by persons with developmental disabilities. It identifies problems of unmet needs and proposes development of a model service system. The plan traces some of the trends which have only recently evolved and which have led to dynamic new ideas about what new expectations we now have for people with developmental

disabilities. It also identifies and describes newer principles that have evolved from the philosophy of Normalization. New technical terms are defined so there is a clear understanding of what qualitative changes must be achieved in order to fulfill our new expectations.

The last section lists four goals that should be achieved in the next five years.

- I. **COMMUNITY INTEGRATION:** All persons with developmental disabilities will receive services in settings that are integrated. The services will provide opportunities to live in a family-scale homes in residential neighborhoods, to participate in a full range of education offerings as children and adults, to work in community businesses, and to engage in the same social and leisure activities available to other community residents.
- II. **INDIVIDUAL CHOICE:** Persons with developmental disabilities will be afforded continuous opportunities and training to make decisions about their lifestyles, relationships and futures. Administrative and resource decisions should directly support the individual with developmental disabilities to grow more self-sufficient through exercising choices.
- III. **SERVICE SYSTEM DESIGN:** The service system will provide adequate capacity and be open to all persons with developmental disabilities as defined in federal and recent state legislation. The developmental disabilities service system will be organized so that policies, regulations and funding incentives provide only services that reflect best professional practice and that document the benefits received and valued by persons with developmental disabilities and their families. These benefits should include consideration of service availability, accessibility, acceptability, continuity, cost and quality as defined in this plan.
- IV. **PERSONNEL STANDARDS:** In recognition of current and future advances in service technology, state, county, and other jurisdictional purchasers of service will develop and require competency standards that reflect job responsibilities and best professional practice. They will hold providers from whom they purchase services accountable for meeting those standards. Individuals who work with persons who are developmentally disabled will accept responsibility for meeting required standards and continuing their professional development to ensure successful client outcomes.

What follows after the goals are a list of six characteristics appropriate service should have so that the goals can be realized. The characteristics are availability, accessibility, acceptability, continuity, cost-effectiveness and quality of services.

Here is an example of one characteristic, its guideline and criteria. By changing each statement to a question, one can determine whether a particular service component has that particular characteristic. If the service being

considered, does not conform, both consumers and providers can work toward the positive change indicated by the guidelines and criteria.

EXAMPLE

Acceptability is a measure of the degree to which services promote genuine opportunities for community integration, self-directed choices and reduction of dependency.

Guideline 3. A comprehensive array of community services should afford persons who are developmentally disabled use of the same resources as, and regular contact with, non-disabled citizens.

- Criterion 1. Services should provide many opportunities for individual choices and options.
- Criterion 2. Services should never be totally segregated in their physical settings nor prevent one's regular interaction with non-handicapped people.
- Criterion 3. The service system should include both formal and informal support networks.
- Criterion 4. Public and private service providers should assume responsibility for promoting public education about the advantages of community integration for the whole community in a manner that minimizes negative reactions from the general public.
- Criterion 5. Service providers should be accountable for reducing their clients' dependencies in terms of quantitative or qualitative measures.

The Metropolitan Council held a public hearing on the plan on July 11, 1985. The public hearing testimony expressed unanimous support for its adoption and provided several suggestions that would improve the document. These suggestions were incorporated in the plan which the Metropolitan Council adopted on September 26, 1985.

The Developmental Disabilities Advisory Committee of the Metropolitan Council hopes that this summary will motivate you to read the plan in its entirety and to use it as a basis for change in Minnesota.

## PRINCIPLE OF COMMUNITY INTEGRATION

A term we've heard many times  
Throughout the past twenty  
Years.

A term which stands for  
The right of all people To live  
according to their  
Personal beliefs and pursuits,  
Ruling out all forms of  
Discrimination based upon the  
Color of one's skin, nationality,  
Political convictions and  
Economic stability.

A term which only recently  
Our society decided to apply  
To persons with developmental  
Disabilities.

And why?

It's because we made such  
People invisible by housing  
Them in institutions.

We didn't think it was  
Our responsibility to examine  
How and why we were the cause  
Of discrimination they  
Struggled with.

We took it upon ourselves  
To feel sorry for them,  
Never asking if they would  
Like to pursue personal  
Goals and learn skills that  
Would enable progress.

We, we, we.

Time is long overdue for  
Us to practice community  
Integration as it is taught,  
And eliminate the handicap  
Of our conscience caused by  
Ignorance.

How do we go about it?

By providing them a home  
With a backyard, trees, and

Flowers in a community neighborhood,  
Rather than an institution.

By providing their parents sufficient  
Financial support to purchase  
Equipment necessary to raise them at  
Home, so they can grow with love,  
Laughter, security, and parental,  
Not clinical, supervision.

By giving them an education at a  
Neighborhood school with their  
Brother, sister, and neighborhood kids,  
Rather than shipping them off to a  
Clinical school specializing in  
Special education.

By giving them the training and a job  
In the real world of business and  
Industry where they can earn a decent  
Salary, rather than encourage them  
To enjoy the boredom of a hobby or  
Instruct them how to appreciate a  
Manual entitled, "The Joy of a Career  
In a Developmental Achievement Center."

By giving them equal access to health  
Services in physicians' offices,  
Community clinics or hospital, rather  
Than make them dread the long bus ride  
Or make their parents, guardians go out  
Of their way investing time and money  
For gas because certain doctors,  
Administrators prefer not to open  
Their doors, doors displaying the  
Invisible sign "For non-handicapped  
People only."

By giving them a religious nurture  
Alongside of us in our church or  
Synagogue where they can have a choice  
To sing in the choir, to serve as an  
Usher, to assist the clergy person in  
Services, rather than receive private  
Religious nurture secluded from others  
Because those without developmental  
Disabilities somehow failed to apply the  
Golden rule to all of God's children.

By giving them the excitement of leisure-  
Time activities not only in their home

But in public parks, theaters,  
Libraries, and sports facilities,  
Rather than the ritual,  
Unstimulating boredom of a  
Television, a few nights a  
Month at a bowling alley, and  
Nothing other than an  
Imagination of what it would Be  
like to see a play at  
Chimera Theater, to head for  
Orchestra Hall and feeling their  
Anticipation mount as the lights  
Dim and whispering voices quiet,  
To be able to tell others how  
Much they enjoy library programs,  
And to score the winning points  
In a basketball game.

They're not asking for much

Only what we take for granted.

Legal rights.

Community integration.

Their time has finally come.

## PRINCIPLE OF ULTIMATE FUNCTIONING

We grow up in a competitive society  
Surrounded with norms determining  
How, when, and why to develop  
Personal skills and behavior in  
Order to survive and succeed now  
And in the future.

Our parents, family members and  
Teachers take the time to teach us  
The rules on how, when, and why.

Most of us develop according to  
The norm, staying on the right  
Track laid out and well used in  
Society.

Most of us have journeys in life  
That are safe, stimulating and  
Progressive.

Far more often than not, we keep  
Looking straight ahead locking our  
Thoughts and concerns on that which  
Only affects ourselves.

In doing so, we make people with  
Developmental disabilities become  
Shadows of fate, placing them in  
Directions that will not be in  
Our way, simply because they are  
Unable to develop exactly  
According to our norm.

Rather than take the time now To design and  
construct tracks To promote their individual  
Development in self-care, learning  
Economic self-sufficiency, independent  
Living skills, mobility, self-direction,  
And receptive, expressive language we  
Continue to ignore their existence and  
Determine the fate of their journey in  
Life.

The principle of Ultimate  
Function Starts with today's  
opportunity to Develop the personal  
skills and Behaviors essential to  
live in Present and future  
environments That mostly include  
non-handicapped People.

They must learn early how to  
Select and pursue goals, and steer  
Their lives in a direction headed for  
Success.

All they ask for are early beginnings  
That will get them as close as possible  
To the norms and patterns of society,  
Ultimate functioning.

We must listen.

We need to learn.

## PRINCIPLE OF ULTIMATE FUNCTIONING

He has a serious form of Spina Bifida.

At birth, his spinal cord resembled the flat shape of a Rubber band, whereas his Parents' resembled the circular Width of one's finger.

Ultimate functioning for Shane Was learning how to use a Caster cart, resembling a Mechanic's creeper or raft, Equipped with a backrest, two Wheels at the end, a front Wheel, and ample space Surrounding his legs.

It is Shane's way to get Around the house, play Outside with friends, and Haul his toys. With his Arms positioned over each Side, and hands placed On the floor, Shane is able to push wherever His caster cart can go.

At fifteen months, the dart And dash stage of development For most non-handicapped toddlers, Shane was able to dart with his Cart and dash with a lash securing His body.

At four years old, when most kids Are Saturday morning cartoon fans, Shane was able to turn channels With a clothespin his parents Attached to the dial, a Challenge overcome through Creativity.

Several special education administrators Opposed Shane's enrollment in a Neighborhood school, claiming he would Do better academically in a special Learning environment.

His parents wanted their son to Learn socialization behaviors through One-on-one contact with non-handicapped Students, rather than be taught how To do so through special education Teachers and books.

Shane's above average academic Performance just slightly dropped at The neighborhood school, whereas his Ability to socialize have scored sky High.

A promising mixture of personal skills And behaviors to function in present And future environments which include Mostly non-handicapped people. Third grade teachers predict Shane will either serve as our nation's President or become a sales executive For a major firm.

Figuratively speaking, he has his feet Well positioned on the ground, running In the right direction.

Way to go, Shane.

Congratulations to his parents.

PRINCIPLE OF ULTIMATE FUNCTIONING

He has autism and is seventeen  
Years old.

Ultimate functioning for  
Eric Was learning how to put  
his Hands to good use and  
Appreciate his ability to  
Control his behavior in a  
Part-Time job at a restaurant  
Working with non-handicapped  
People, rather than be taught  
How to prevent self-injury by  
Putting his hands in his  
Pockets or by folding them  
Without an opportunity to  
Progress in the real world  
Showing his ability to do so.

Eric thrives on going to the bank,  
Meeting people, and talking about how  
He controls his behavior at work.

Way to go Eric.

Congratulations to his parents and  
Employer.

## PRINCIPLE OF ULTIMATE FUNCTIONING

He has severe cerebral palsy.

Ultimate functioning for Paul  
Was learning how to make it to  
The top by carrying his own  
Weight rather than being  
Taught how to adapt to a  
Lifestyle almost 100% dependent  
On others.

After a year and a half of  
Hard practice, Paul can carry  
His body up and down fifteen  
Stairs, around the house,  
Make his bed, wash clothes and  
Dishes, clear the table and  
Empty wastebaskets.

Way to go Paul.

Congratulations to his parents  
Brothers and sisters for taking  
The time to show their love.

## PRINCIPLE OF ULTIMATE FUNCTIONING

She has mental retardation, and  
Is nine years old.

Ultimate functioning for Kristina  
Is learning how to count,  
Using real life experiences  
Rather than be taught  
How to count blocks.

Ultimate functioning for Kristina  
Also is learning how to write her  
Name by practicing how to draw  
Lines between dots mapped out  
For the letters K,r,i,s,t,i,n,a  
Rather than be taught the  
More difficult way of drawing  
Letters.

She's proud to be able to  
Count and measure food and  
Water for her dog and cat.

She was thrilled to give her dad  
A valentine signed "Love, Kristina."

Way to go, Kristina

Congratulations to her parents and  
Teacher.

## PRINCIPLE OF ULTIMATE FUNCTIONING

She is legally blind, has  
Mental retardation, a short  
Memory span, cannot read, and  
Lived in an institution for  
Forty years.

Ultimate functioning for Mary  
Began late, but not too late,  
Memorizing cards picturing tasks  
Of her first job in domestic  
Services.

Within two weeks Mary had the  
Tasks cards memorized, proving to  
Herself that something associated  
With success can be memorized.

She earned a well-deserved raise  
In just six months  
Ultimate functioning gave her a  
Chance to become someone.

Way to go, Mary.

## PRINCIPLE OF PARTIAL PARTICIPATION

As I tuck you into bed,  
The fear silently captures  
My thoughts.

The fear that you will be  
Denied a right to participate,  
To whatever extent is possible,  
In the life of our community.

The fear that many Non-  
handicapped persons will  
Reject rather than help  
Fashion adaptations for  
Activities and environments  
Which enable you to participate  
In some way, using the same  
Community resources they use.

You're such a beautiful  
Daughter, Bridget, thriving  
As non-handicapped children  
Do on the excitements of  
Learning, experimentation,  
Playing, friendship, being  
Loved and sharing love.

I see how much you enjoy  
The pleasure of learning I watch  
your desire to Become autonomous  
develop,  
Wanting to psychologically  
Stand on your own two feet.  
Everyday you look forward to  
Playing with your dad, myself  
And friends, the smile on your  
Face radiates when friends  
Knock at the door, all  
Normal, positive expressions  
Of life.

You were born with (type of DD),  
Bridget, not cursed with it.

Your dad and I promise you with all  
The love in our heart that we will  
Diligently try to match your  
Determination to thrive with our  
Effort to enforce your right to  
Live as non-handicapped children.

Fear is what we allow it to become,  
Bridget.

Hopefully, the day will soon come  
When those who choose to interfere  
With the principle of partial  
Participation will regret their lack  
Of understanding and strive to improve  
Errors, we will welcome them, not  
Reject them.

Look forward to sharing tomorrow with  
You. Pleasant dreams, my daughter.

The principle of partial participation  
Requires that adaptations to activities  
And environments be made for individuals  
So they can participate in some way,  
Using the same community resources  
Available to those who are not  
Handicapped. This principle affirms  
That persons with severe mental or  
Physical handicaps have a right to  
Participate, to whatever extent is  
Possible, in the life of their  
Communities.

## PRINCIPLE OF PARTIAL PARTICIPATION

At the age of fifteen she became A  
person with epilepsy. Within  
One year memory loss began, a  
Learning disability caused by  
Anti-seizure medication.

Partial participation for Sheila  
Was learning how to adapt to  
Her learning disability by using  
A tape recorder in class to serve  
As a backup for her memory.

During the first year of her  
Learning disability, Sheila's  
Grade point average fell from 3.10  
To a 1.68.

Because a teacher was able to  
Identify her learning disability and  
Sheila had the courage to use a  
Tape recorder, her grade point  
Average managed to reach a 3.0

Her hope to attend college is not lost.

Way to go, Sheila. Congratulations to her  
teacher.

Partial Participation affirms  
Each person's right to  
Adaptations needed  
To participate in the same  
Opportunities that everyone else  
Uses to develop and become  
Valued members of their communities.

## PRINCIPLE OF PARTIAL FUNCTIONING

She has a hearing and speech  
Impairment. At the age of  
Thirteen months, a critical  
Infection silenced her ears to  
The sounds we hear, express, learn  
Through, and function by.

Partial Participation for Sarah  
Is sign language, picture cards,  
Role playing, blinking light  
Fixtures, and a dog trained to  
Notify her of significant sounds.

Through sign language, Sarah will  
Learn how to communicate in the  
World of sound, using her hands  
To speak.

Her parents felt lost for words  
To describe their joy the first  
Time Sarah learned to say, "Hi,  
Mom and dad."

Picture cards will teach Sarah the  
Visual image and definition of words,  
Helping her work through the  
Complexity of those spelled the same,  
But with different meanings.

She'll learn that the word, bow  
Defines the ribbon in her hair.

The equipment her dad uses to hunt  
Deer, and, the courtesy movement  
Her brother makes following his  
Piano performances.

Role playing will help Sarah  
Learn and apply words associated  
With specific functions, teaching  
Her communication skills for  
Roles she will assume as a child,  
Teenager, and an adult.

Blinking light fixtures located  
Throughout her home will encourage  
Sarah to seek independence with  
Confidence, spending time doing  
What she'd like in rooms by Herself.

They give her and her parents a security  
In knowing a light will blink  
Whenever attention is desired.

A dog trained to notify Sarah of  
Significant sounds will promote  
Self-care by giving her an opportunity  
To handle responsibilities that require  
Hearing.

Her pet keeps an ear open for a fire  
Alarm, a weather warning, someone  
Knocking at the door, the alarm clock,  
The stove's timer, and the presence of a  
Person walking behind Sarah.

Sarah just celebrated her sixth  
birthday.

She's always on the go to learn words,  
She always has something to say, she's  
Eager for role playing, she enjoys  
Drawing picture cards with her parents,  
She has her operation of the blinking  
Light fixtures down pat, and she walks  
Around the block in pride with her dog.

Through adaptations, Sarah can  
Hear and express the sounds of life  
With a stronger appreciation than some  
Persons who can listen and talk with  
Little effort.

Way to go, Sarah. Congratulations  
to her parents.

## PRINCIPLE OF NATURAL PROPORTION

Sitting alone in the reverend's  
Office, her fingers crossed,  
Hoping that her prayer will be  
Answered. She wants more than  
Anything to assist in church  
Services.

The reverend arrives. Tension  
Begins as he is gently trying  
To explain how it would be best  
To set aside her goal, pointing  
Out how some parishoners will  
Be distracted during services  
By the complications of her  
Disability  
Or for epilepsy write:  
In seeing a generalized tonic  
Clonic seizure.

She can't hold back the tears.  
This creation of God wants  
So very much to fulfill her  
Goal. She's grown tired of  
Just doing things that  
Persons with developmental  
Disabilities are allowed to do,  
Rather than what she wants.

Silently she ponders the  
Questions. "Would God be  
Distracted by a person with a  
Disability?" "Would God prevent  
Me from obtaining my goal?"

She musters enough courage to gently  
Explain to the reverend that God knew  
All along that she would have disability  
That God would encourage, not prevent  
**Her, from obtaining the goal. That God  
would reach out to parishoners,  
Calling upon them to treat her as they  
Do all others.**

**Her words were heard. A program was  
Designed to teach her lessons on church  
Services. The reverend called upon  
Parishoners to respect her determination  
to seek and fulfill a meaningful goal.**

**The principle of natural proportion was  
Applied. God must have smiled.**

**The principle of natural proportion says  
That persons with developmental  
Disabilities should regularly interact  
With more non-handicapped people than  
Handicapped people approximate to that  
Ratio in the total population.**

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