# AUTISTIC PEER SUPPORT

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#### **BEING AUTISTIC ON ONE'S OWN**

**Refuge from NT demands** 

Control over the space itself, what we do in our space, and who comes into our space

**Decreased external structure** 

**Possible boredom or loneliness** 

Difficulty managing routine maintenance and self-care

**FREEDOM** 

CHAOS

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# **BEING AUTISTIC AMONG NEUROTYPICALS**

Being confused	Being "special"
Being overwhelmed	Being admired
Being isolated	Being cared for
Being excluded	Being allowed greater latitude
Being devalued	Being among people who are less confused and overwhelmed, more oriented, and able to help

#### **BEING AMONG AUTISTIC PEERS: BENEFITS AND CHALLENGES**

Autistic Similarities Other people who are like ME!!!

Acceptance of Differences It's okay for me to be weird!

**Presumption of Ability** 

People aren't automatically assuming I'm helpless. People expect me to be capable. Maybe I *am* capable after all!

Autistic Competence People "like me" can be strong and capable. Maybe *I* can be strong and capable too!

Acknowledgment of Difficulties I'm "allowed" to ask for help, even if I'm "highfunctioning"!

#### Reciprocity

I'm not just receiving help, I can help others too!

Autistic Variability We're not only different from NTs, we're different from each other. Some people are really weird!

Expectation of Tolerance I need to accept other people being weird too.

Presumption of Ability People may not notice that I need help, or may not know how to help me.

Stressed/Overloaded Peers People are dealing with their own stuff and may not

have spare energy to help me, even if I can explain what I need.

Individual Responsibility for Support Needs It's my responsibility to communicate my needs. I may not know what I need!

Loss of "Specialness"

I'm not the neediest person here. People are not going out of their way to care for me, are not letting me get away with stuff, and are not admiring me when I do things for myself.

#### AUTISTIC SPACE

VS.

**Designed by autistics** 

Autistics decide what we need and want

Autistics make the decisions and rules

Autistics do things for ourselves and each other

Autistics expect to be empowered and selfdirecting

#### PLACES FOR AUTISTICS

**Designed by NTs for autistics** 

NTs decide what is best for autistics

NTs make the decisions and rules

NTs do things for us

Autistics are seen as helpless and dependent

# AUTISTIC PEER INTERACTIONS

Information and Orientation	Social Differences	Expectactions/Goals
Lots of information in advance	Interest levels	Self-monitoring
Lots of information in	Initiation and response	Plan for your own support needs
written or visual format	Focus and interests	Say what you mean
<b>Orientation sessions</b>	Number of people	Communication is the
Lots of opportunity to ask questions	Prosopagnosia	responsibility of the individual, not the group!
- Support for transitions	Nonverbal communication	Ask, don't assume!
	Warmup time	
	Down time	
	Autistic social rules	

# THE PEER EXPERIENCE

"Despite thousands of miles, our 'our world' concepts, strategies, and experiences even came down to having created the same made-up words to describe them. Together we felt like a lost tribe. 'Normal' is to be in the company of one like one's self."

Donna Williams, Somebody Somewhere

"We all had a sense of belonging, of being understood, of being normal . . . all the things we could not get from others in general. It was so sad to have to leave. 'Why can't we all live together?' we had each asked at some point or other."

Donna Williams, Somebody Somewhere

"For me, this day will become an anniversary that I will celebrate with great joy. It marks the beginning of not being an alien. It will be a day of validation. A day to set aside and remember." Katherine French, "My Personal Holiday"

"In many cases, the person would express a feeling of finally finding his own kind, as if he or she was an alien who had been stranded on this planet, and now has found other aliens who were from the same planet."

Sola Shelly, "Cousinhood: Who cares and other questions"

**Comments from Autreat Participants:** 

"This was the first place I wasn't criticised for being different."

"It showed me that being me was okay, and that my ways of doing things weren't 'wrong' or 'defective,' just different, and perfectly all right."

"For the first time, I had my less than 'normal' attempts at communication recognized, and also accepted."

"We loved the feeling of being accepted and liked for being ourselves!"

"Here people who could paint and draw equally shared experiences with those who can't hold a pencil or a brush. People who are very articulate equally shared experiences and understood those who could only jump or clap their hands or point to letters on a letter board or picture board to respond to a question."

### **RECOMMENDED READING:**

Autism Network International: The Development of a Community and its Culture, Jim Sinclair, www.ani.ac/ History\_of\_ANI.html

Being Autistic Together, Jim Sinclair, http://www.dsq-sds.org/article/view/1075/1248

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### WHAT ARE THE QUALIFICATIONS FOR PEER SUPPORT PROVIDERS?

Being autistic is not enough. If you know about one autistic person, you know about one autistic person.

Autistic providers should be screened, TRAINED, and supervised to the same standards as other providers.

No ceiling: Autistics can be highly educated professionals.

No floor: People (including autistics) can be paid service providers, volunteer peer helpers, or mentors without requiring advanced academic education.

**Examples among Autreat 2010 participants:** 

Occupational therapist Counselor Teacher Teaching assistant Personal care attendant Children's librarian School bus monitor Parents Siblings

### **BARRIERS TO EFFECTIVE PEER SUPPORT**

**Presumption of inability** 

All-or-nothing thinking—many autistic people are not able to help others because we're not getting the support we need ourselves

Unavailability of peer support training

Inadequate support for necessary education/training

**Inadequate vocational services** 

#### RECOMMENDATIONS

Incorporate autistic people and autism services into CIL services

Improve meaningful independent living skills training for autistics to reduce intensity of support needed (autistic mentors can train others)

Support existing autistic peer support networks

Develop training for autistic peer support (experienced autistic providers can provide training)

Encourage and support interested autistic students to pursue career goals in service and support

Improve HCBS and vocational rehabilitation services to increase pool of autistic people who are in a position to help others

**INVEST IN AUTISTIC CAPABILITY!** 

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