

— YAI —
NEW YORK CITY
AUTISM
CONFERENCE

The Sexual Rights of Adults with Autism and Access to Sexuality Supports and Services

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Let's Talk About Sexual Rights & Sexual Self-Advocacy

Today's Roadmap:

- What Is Sexual Self-Advocacy?
- Home and Community-Based Setting Rule and How It Can Impact Residents' Sexual Rights And The Role of the Provider
- OPWDD – Considerations Concerning Sexual Contact and Consent
- Sexuality Services and HCBS Waivers
- When Can Sexuality Services Be Limited or Restricted?
- What If Resident Is Arbitrarily Denied Right to Express Sexuality or Receive Sexuality Supports?



Let's Talk About Sexual Rights & Sexual Self-Advocacy

On March 21, 2014 people with intellectual and developmental disabilities gathered at the Institute on Disability and Human Development (IDHD) to talk about sexual self-advocacy. This video produced by the Sexuality and Disability Consortium (SDC) describes what they think sexual self-advocacy is and what would help them be a better sexual self-advocate.

[In My Voice: Sexual Self-Advocacy: https://youtu.be/M5Q5hW62M4Y](https://youtu.be/M5Q5hW62M4Y)



WHAT DOES SEXUAL SELF-ADVOCACY MEAN TO YOU?

1. Right to be your true self
2. Right to be intimate with my sexual partner, regardless of sex or gender
3. Choice of where to live
4. Access to information about sexuality and safe sex
5. Right to Privacy
6. Ability to hug and kiss someone I care about and who cares about me
7. Right to have children

HCBS SETTINGS RULE

- Established in 2014. States have until March 17, 2022 to demonstrate compliance with final rule.
- States must submit evidence to CMS that **waiver services are being delivered in community-based residential settings**, that comply with the requirement of the HCBS Settings Rule.
- If states fail to comply, the federal government may withhold Medicaid reimbursements for services administered through the waiver program.

“In this final rule, **CMS is moving away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of individuals’ experiences.** The home and community-based setting provisions in this final rule **establish a more outcome-oriented definition of home and community-based settings**, rather than one based solely on a setting’s location, geography, or physical characteristics.” Fact Sheet,

Summary of Key Provisions of the HCBS Setting Final Rule (Jan. 10, 2014).



HCBS SETTINGS AND HOW IT CAN IMPACT RESIDENTS' SEXUAL RIGHTS & THE ROLE OF A PROVIDER*

If you live in a **certified setting** or a **provider managed setting like a Group Home** or an **apartment owned by a provider** –

YOU HAVE RIGHTS!

**Information adopted from presentation by Cathy Holmes, Standards Compliance Analyst 1, OPWDD, Division of Quality Improvement/Continuous Quality Improvement*

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KNOW YOUR RIGHTS IN HCBS SETTINGS!*

- To **make** your **own choices**
- To **express your sexuality** the way you want to express yourself (gender presentation, what to wear, your hairstyle, etc.)
- Make **decisions about YOUR individualized service plan.** Who's life is it –it's YOUR life!
- To **choose** the **services!**
- To **choose** your **goals!**

** Information adopted from presentation by Cathy Holmes, Standards Compliance Analyst 1, OPWDD, Division of Quality Improvement/Continuous Quality Improvement*



**CAN YOUR HCBS RESIDENTIAL SETTING
ARBITRARILY DENY YOUR RIGHT TO EXPRESS YOUR
SEXUALITY OR RECEIVE SEXUALITY
SERVICES OF SUPPORTS?**

NO!!!!!!

... YOU HAVE A RIGHT TO

- **Privacy** including locking your apartment, bedroom and bathroom door and which staff should have access to your keys;
- Having **private conversations** on the telephone/internet and with your visitors;
- **Decorate and furnish your bedroom** the way you want to;
- **Visitors** at any time;
- To **move freely** anywhere within and outside your home;
- **Physical accessibility** to all of your home's features



THE HCBS SETTING RULE APPLIES TO *NON-RESIDENTIAL SETTINGS*

Center for Medicaid & Medicare Services clarified that the **HCBS Setting Rule** applies to all settings where HCBS are delivered, not just to residential settings.

OPWDD APPENDIX 11 - Considerations Concerning Sexual Contact and Consent

FREEDOM TO EXPRESS SEXUALITY

People with developmental disabilities are presumed to have the ability to make decisions about some or all aspects of their lives.

- However, some people with developmental disabilities may, in fact, not have the ability to make decisions regarding some or all aspects of their lives, including sexuality.
- Providers are expected to both respect the decisions and choices made by persons with the ability to do so (**even when they disagree with those decisions or choices**) and to ensure that protection is afforded to those persons who do not have the ability to make some decisions.

OPWDD APPENDIX 11 - Considerations Concerning Sexual Contact and Consent

No person shall be denied the right to access

- clinically sound instructions on the topic of sexuality and family planning services and information about the existence of these services,
- including access to medication or devices to regulate conception.

A person's rights also include the freedom to express sexuality as limited by one's consensual ability to do so, provided such expressions

- do not infringe on the rights of others; and the right to make decisions regarding conception and pregnancy pursuant to the mandates of applicable State and Federal Law

Where is OPWDD Now on Considerations Concerning Sexual Contact and Consent & the HCBS Settings

Rule? New York State Department of Health, HCBS Final Rule (updated September 2017)

- **Rights of HCBS Recipients:** Several commenters expressed concerns with regard to individuals' rights in the Statewide Transition Plan, including people's right to privacy and sexual expression, and rights restrictions due to the needs of another.
- **Response:** New York **is actively working to achieve state regulatory alignment and consistency with the HCBS rule** and will ensure that there is a thorough review of the regulation components noted by the commenters. **OPWDD's ADM #2014-04 provides guidance on rights modifications under the rule.** If there are rights modifications that affect others in the home, the expectation is that the provider works with all involved to safeguard others' rights. This will also be addressed through **future regulatory revisions.**

SEXUALITY SERVICES & HCBS WAIVERS

Snapshot Reality of Access to Sexuality Services through the HCBS Waiver Program:

- Of the 111 Medicaid HBCS waivers for people with IDD offered in FY 2015, less than 12% provided any type of sexuality-related service.
- FY2015, thirteen HCBS IDD waivers (11.71%) from seven states and the District of Columbia offered 37 sexuality-related services in FY 2015.
 - **Ninety-two percent (n=34)** of services were **reactive services** aimed at preventing and stopping inappropriate behaviors.
 - **Only 8% of services (n=3)** were more **positively oriented, with purposes related to education and awareness**.*

Statistics appear in article by Carli Friedman & Aleksa L. Owen, *Sexual Health in the Community: Services for People with Intellectual and Developmental Disabilities*, 10 DISABILITY & HEALTH J. 387, 389 (2017).

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SEXUALITY SERVICES & HCBS WAIVERS

Snapshot Reality of Access to Sexuality Services through the HCBS Waiver Program:

- In this study, the majority of HCBS **sexuality-related services** were **embedded** within another service, **such as habilitation**.
- Stand alone sexuality services projected approximately \$646,000 of funding in FY 2015 or less than 0.01% of total HCBS IDD waiver.

Statistics appear in article by Carli Friedman & Aleksa L. Owen, *Sexual Health in the Community: Services for People with Intellectual and Developmental Disabilities*, 10 DISABILITY & HEALTH J. 387, 389 (2017).

SEXUALITY SERVICES & HCBS WAIVERS

- Sexuality services could fall into any number of the HCBS waiver categories below:
 - residential habilitation; individual goods and services; prevocational; transportation; self-advocacy training; day habilitation; community transition supports; respite; health and professional services (crisis, dental, clinical and therapeutic services, nursing and home health); supports to live in one's own home (companion, homemaker, chore, personal assistance, supported living); care coordination; adult day health; specialized medical and assistive technologies; financial support services; family training and counseling (family training and counseling, family supports); recreation and leisure; and, supported employment.

WHEN CAN SEXUALITY BE LIMITED OR RESTRICTED?

- The expression of sexuality can also be reasonably limited or restricted, including the time and location, in accordance with a plan **necessary for the health and wellbeing of the individual** . . . 14 NYCRR Section 633.4.
- If limitations or restrictions are necessary . . . **cannot be done for disciplinary purposes, retribution, or the convenience of staff**. In addition, any limitation of a person's rights must be on an **individual basis**, for a **specific period of time**, and for **clinical purposes only**.

What If I Am Arbitrarily Denied the Right to Express My Sexuality or to Receive Sexuality Supports?

- Objection to any part of a person's individualized service plan can be made by the person or other parties. 14 NYCRR Section 633.12.
- **OPWDD Objection and Hearing Process.** (1) **Demand a meeting**, (2) **bring someone you trust to the meeting** and (3) **demand sexuality supports and services in your ISP** (informal meeting with provider; (4) **If get nowhere** with agency – **Right to Formal OPWDD hearing.**
14 NYCRR 633.12.



**THE DISABILITY & CIVIL RIGHTS CLINIC
IS HERE FOR YOU!**

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Finding Out Your Rights and About Sexuality Supports and Services

- As you see from the In My Voice Video, **Knowledge, Training and Support** in this or any area is key to promoting independence and safety!
- It is always a good idea to request a copy of the Relationship and Sexuality Consent Policy of any agency you are involved with. Why?
- It helps agencies who provide services to people diagnosed with developmental disabilities respond more consistently and seeks to avoid judgment of the person's beliefs and/or actions.
- In YAI's Policy, it clearly states "Adults with developmental disabilities have the right to make their own decisions about relationships. A person with a developmental disability has the right to engage in sexual activity with another person providing he/she is capable of providing informed sexual consent."



Age of Consent in New York State

- **The Age of Consent in New York State is 17 years old.** In the United States, the age of consent is the minimum age a person is considered legally old enough to consent (agree) to participate in sexual activity.
- Individuals aged 16 or younger in New York State are not legally able to consent to sexual activity.
- **There are No Laws in New York State that allow sexual relations when one person is 16 and the other is 17 or 18 years old.**



The Ability to Give Consent

- It is presumed that a person **Without** a developmental disability diagnosis and/or a cognitive impairment has the ability to consent to a sexual relationship once they reach the age of consent in their State of Residence. (17 y/o in NYS)
- If a person is diagnosed with a developmental disability and/or a cognitive impairment their capacity to consent to a sexual relationship is **No Longer Presumed** and **Training to Make Informed Decisions is Needed**.
- Determining the ability to give Sexual Consent varies from State to State.
- In addition to a Relationship and Sexual Consent Policy, YAI has a Sexual Consent Determination Tool that follows the recommended teaching topics from the Office of People With Developmental Disabilities (OPWDD)...



YAI's Sexual Consent Determination Tool

- Indicator #1

The individual has an awareness of the nature of the sexual act under consideration and of having the choice to engage in or abstain from the type of sexual contact under consideration.

- It is important to keep in mind The Difference Between Affection and a Sexual Act. Physical Affection such as a Hug or a Peck on the Cheek or Lips **DOES NOT** Require the Ability to Give Consent, just a Willing Partner.



YAI's Sexual Consent Determination Tool

- **Indicator #2**

The person has an understanding of how to prevent unwanted pregnancy and diseases which are sexually transmitted.

- **Indicator #3**

The person has an understanding of the need for restriction of sexual behavior as to time, place, or behavior. (For Example: Public vs. Private, Leisure vs. Work, School or Program Time.)



YAI's Sexual Consent Determination Tool

- Indicator #4

The person has an understanding that certain sexual activities are against the law and could result in or have dire consequences.

- Indicator #5

The person has an understanding of being at risk in a potentially harmful/abusive/exploitive sexual situation and is capable of making a reasonable plan for removing him/herself in the situation.



Possible Sexual Consent Determination Findings

- **Level A- The person is able to verbally give informed consent without any needed follow up.**

or

The person is able to verbally give informed consent, however, they can benefit from further training/counseling for Indicators # _____ (See Provided Recommendations)



Other Possible Sexual Consent Determination Findings

- Not yet able to determine verbal informed consent, further exploration is needed. (See Provided Recommendations)
 - Not able to verbally give informed consent, needs to be evaluated using the Tool for Assessing Informed Sexual Consent through an Evaluation of Responsible Sexual Behavior (Level B).
 - Not able to give informed consent at this time. (See Provided Recommendations)
- 



Remember To

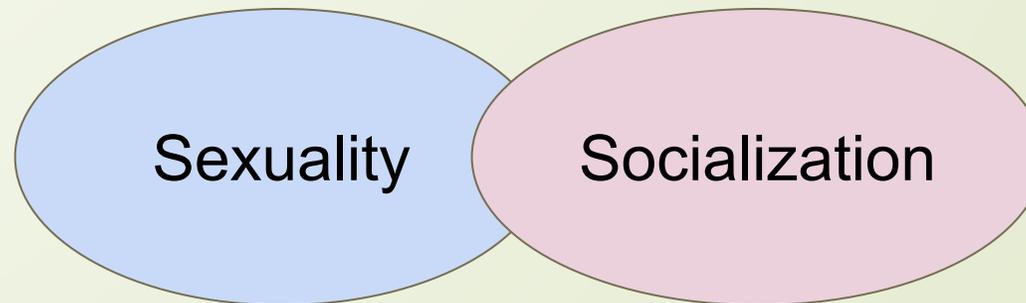
- **Speak with your loved one's Medicaid Service Coordinator (MSC) about Sexual Consent Determination when the person is approaching age Seventeen or if they are older than Seventeen.**
 - **Request a copy of the Relationship and Sexuality Consent Policy of any agency you are involved with. (Including the School)**
- 



Other Sexuality Supports and Services

It's Not Just About Sex!

Social Concepts (Friendships, Social Skills) are as Important as Sexual Concepts (Masturbation, Pregnancy Prevention).





Importance of Addressing Sexuality Issues

- Individuals with autism **physically** mature at about the same age as their neurotypical peers.
- Sexuality issues will not go away, therefore we need to address them.
- Decreases the Likelihood of Abuse.
- Combats Myths & Misinformation. (Misconceptions)
- Promotes Social Skills, Personhood, Happiness.
- Reduces Fear, Anxiety, and Worry.
- Increases Self-Awareness, Self-Esteem and Gender Comfort.
- Allows for Maturity, and Healthy Relationships.



Caregivers' Most Common Concerns

- Touching private parts
- Disrobing
- Masturbating in public
- Touching others and/or the opposite sex inappropriately
- Masturbating with odd objects

Female: Pregnancy (being taken advantage of). Need for birth control.

Male: Being taken advantage of by another male. Managing masturbation.



Important Concepts to Teach

- Private vs Public
 - Understanding and Developing Relationships (Friendship & Romantic)
 - Use of Social Judgment
 - Importance of Personal Hygiene
 - Assisting with Self Care while Teaching Boundaries
 - Prevent Sexual Exploitation
 - Safety
- 



Components of the Sexuality Program

- Body Image
- Self-Esteem
- Being Healthy
- Hygiene
- Puberty
- Social Skills
- Private vs. Public
- Sexual Orientation
- Menstruation
- Abuse Prevention
- Masturbation
- Relationships & Boundaries
- STDs, Birth Control, Pregnancy
- Internet Safety
- Right and Responsibilities of Sexual Behaviors



Safety/ Reporting

Safety

- Abuse
- Generally saying NO to inappropriate touches, languages, etc
- Knowing how to report and feeling safe doing so

Reporting

- Teaching how to report
- Teaching is okay no to listen to authority figures

Supports and Services



In-Home Sexuality Training

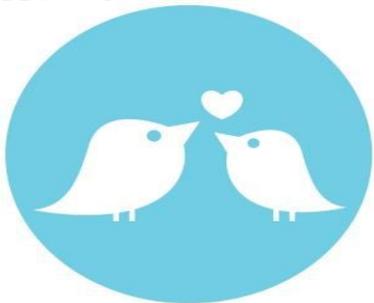
In-home sexuality education and training is available for people ages 9 and up. Individual assessments and training plans provided. Topics covered include: the body, hygiene, puberty, personal identity, boundaries, abuse, relationships, and more.

Project Grown-Up

Prepares a parent for dealing with issues around their child's physiological development. The group training sessions assist parents in addressing the interpersonal and autonomy issues of relationships and sexuality with their children.

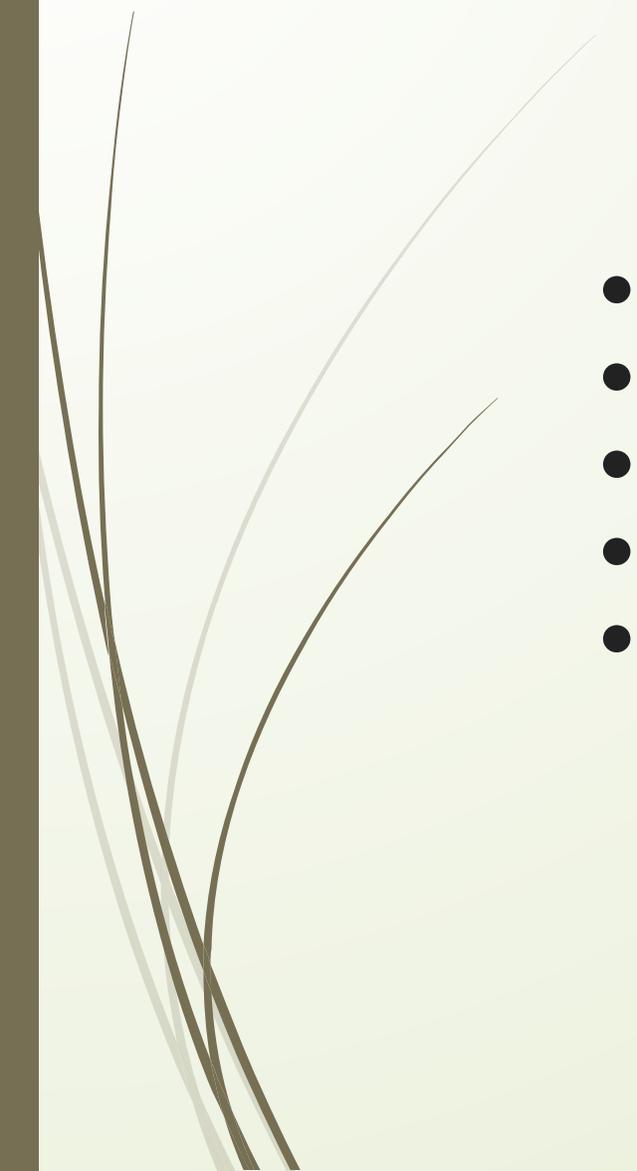
You and I

This group offers adults the opportunity to learn social and dating skills in a structured setting. Monthly events are open to people who are 18 and older living at home with their family in Manhattan and are eligible for OPWDD services.





Teaching Social Skills

- Relationships, DATING
 - Greetings, conversations, phone, email, chat skills
 - Social distance
 - Empathy
 - Flexibility
- 

Supports and Services

Independent Living Program (ILP) - NYC (ILP)

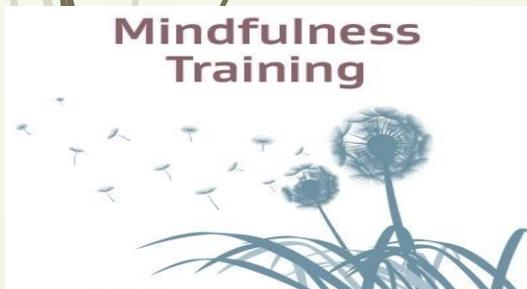
A course which provides the opportunity for adults, 18 years of age and older, to learn and develop in a group setting.

Transition To Independence

For ages 17-21 on the autism spectrum. Includes Yoga & Mindfulness, Life Skills and Kitchen Skills

Mindfulness Training Training and workshops

For parents and people with intellectual and developmental disabilities. Mindfulness is a way of relating directly to whatever is happening in your life, meeting your experience skillfully and with an open heart. It is a skill to help handle the stress of everyday life and an antidote to the habitual response patterns that lock us into routines that undermine emotional and physical health.



Socialization Services

Leisure Connection

A recreational program for adults, ages 18 and up, with a high level of independence who live in and around New York City. This program provides intellectually and culturally stimulating social and educational opportunities that encourage meeting new people, making friends, and developing lifelong social skills. They meet the third Saturday of each month and the group is unchaperoned.

Leisure Trax

Offers adults with developmental and learning disabilities vacation and travel opportunities, including weekend trips and extended vacations with domestic and international destinations. Free travel (some trips) offered.

Leisure Tracks

A recreation and socialization program for people, ages 16 and up. Members need to be travel trained or transported to the program by a family member. Activities focus on community outings and a variety of recreational activities. Fun and practical experience are key program components.

MAC (Mainstreaming At Camp) In partnership with the Frost Valley YMCA sleepaway camp. Offers an award-winning inclusive camping experience in the Catskills to children and teens with developmental and learning disabilities, ages 8 and up.



Respite Services



Holiday Respite

A holiday recess recreation program for school-age children during school breaks.

After School Respite

This afterschool program offers a variety of educational and recreational activities to children and adolescents.

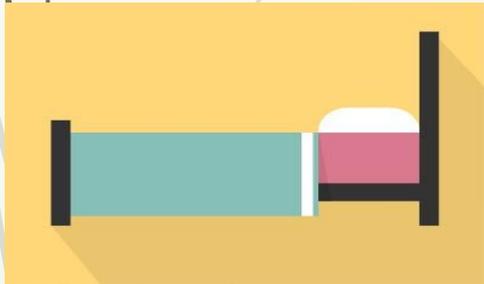
Overnight Respite

Is offered for up to 2 weeks at a time in a wheelchair accessible facility in LeFrak City, Queens for Brooklyn and Queens residents, ages 12 and up. This program is located in an area with access to numerous recreational opportunities.

Club Fun

A wide variety of Saturday recreation programs for children and teens, ages 6-18.

This club provides ongoing support to adults, ages 16 and up, with a mild disability through recreational/cultural activities and discussion groups for increased self-awareness. Activities include arts and crafts, drama groups, trips, ball games, and other community events.



Socialization Services



Adult Recreation

These programs offer recreation activities and socialization opportunities for people, ages 16 and up.



Hankering For More

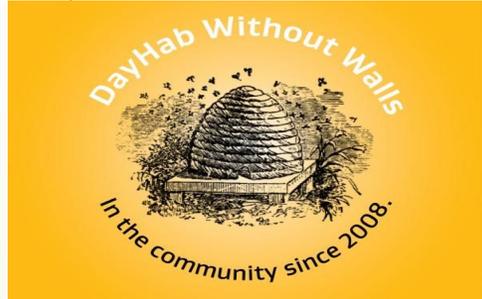
Hankering For More's primary goal is to help its adult members spark social connections with peers that allow them to create and maintain their own social network without staff support and outside of formal HFM events



Recreation Services

This club provides ongoing support to adults, ages 16 and up, with a mild disability through recreational/cultural activities and discussion groups for increased self-awareness. Activities include arts and crafts, drama groups, trips, ball games, and other community events.

Supports and Services



Day Hab Without Walls - RCAPD

Day Hab Without Walls offers individualized and group activities designed to teach life and community safety skills, build relationships, promote independence, provides volunteer opportunities and vocational skill building. The focus is on each person's strengths while participating in the larger community. 21+



Social skills groups for adolescents and young adults with Autism. Group topics include friendships, communication, social boundaries, awareness of others and assertion/choice making.

YAI ARTS

YAI ARTS is an innovative arts program in New York City for adults with intellectual and developmental disabilities looking to develop their creative voice and become working artists.

Operating as an open studio, YAI ARTS champions individual self expression, encouraging artists to work with the media and topics of their choosing. Artists receive mentorship, portfolio development, access to materials, workshops, art critiques, and field trips to galleries and museums.

YAI ARTS

Supports and Services

Friday Night Social

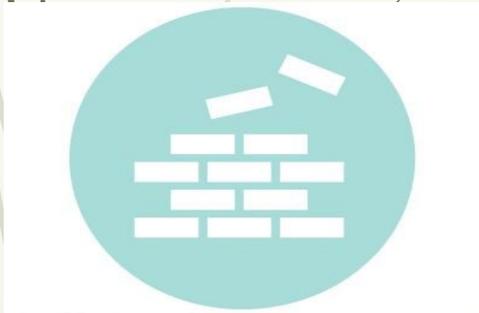
Friday Night Social is a respite program, which takes place on Friday evenings. The Social offers the opportunity for young adults to socialize and meet friends, develop various personal and interpersonal skills, and explore their creativity. The program is also self-directive, plan determined according to the interests of the group participants.

Asperger's Skill Building Network

An experiential program for adults designed to improve social skills vital for friendship and work. Two staff members facilitate groups focusing on various themes: team building, real-life scripts, stress reduction techniques, and community outings.

Parents with Special Needs (PWSN)

In-home and community-based training program designed to empower mothers and fathers with a developmental disability who need support in improving the parent-child relationship



Supports and Services

Coffeehouse Program - New Jersey

The Coffeehouse program for adults provides an environment where participants can expand their social circles and become active members of the community. The program includes activities focusing on improving self-esteem, maturity and independence.

10 Pins Bowling

A weekly program held in Rockland County for adults (21+). It offers the opportunity for participants to socialize and bowl in a non-competitive environment. It takes place at a local bowling alley on Sunday mornings from September to May. Bowlers pay a weekly league fee.

Behavior Management A short-term training program that provides support to families dealing with challenging behaviors. Training is geared toward supporting caregivers and direct services providers.





Last But Not Least...

- Be Proactive, Not Reactive: Teach the Concepts *Before* the Issue Presents Itself!
- Stay Neutral; Avoid Judgment.
- Use Teachable Moments
 - When Asked Specifically
 - When Behavior Indicates Need
- Model Appropriate Boundaries by Choosing Private Locations to Discuss Topics and/or Issues.
- Use Repetition, Especially with Key Concepts.
- Teach Complex Tasks in Simpler, Individual Steps, and In Chronological Order.