Assessment tools to promote effective services and treatment of people with IDD and Behavioral Health Needs Part II

Presented by:

Members of the National START Network located in North Carolina, Arkansas, Virginia and New Hampshire

Brief Overview

- START programs utilize various assessment tools and strategies to assist in promoting effective services and treatment.
- We will review the use of the following tools and methodologies:
  - The Aberrant Behavior Checklist
  - The MEDS
  - Emergency/crisis assessment strategies, and
  - Data collection and reporting at the START Therapeutic Resource (Respite) Center

Aberrant Behavior Checklist (ABC)
Application within START Model

Jill Hinton, Ph.D
Center for START Services, National Team Member

Anne LaForce, LPA
NC START Central, Clinical Director

ABC

Aman & Singh 1986

• *Informant scale*: caregiver independently completes the form

• Aims to capture specific **behavioral** symptom areas

• Developed on normative data from institutions and later data for group homes

• Widely used, over 250 published papers using the ABC

Using informant rating scales

Informant:

•How well do they know the person?
•Are they eager to do this work for you?
•Do they have the academic skills
•required?
•Did they read all the material?
•Is the setting within which they complete
•the scale quiet with no pressures?
•Are you available for questions?

ABC form has 58 items & 5 subscales

Subscale	Number Items
•Irritability	15
•Lethargy	16
•Stereotypy	7
•Hyperactivity/Noncompliance	16
•Inappropriate Speech	4

Steps to use ABC

- Explain the importance to informant
- Insure the informant knows the person well
- Provide quiet space, time, writing area, **ruler** for ease of completion
- Provide *"Individual Items with Specific Examples"* in sheet protector
- Thank informant and tell the results and how they will be used in simple terms

Interpreting the ABC

- ABC is best interpreted as an indicator of types of problem behaviors and then used for tracking improvement or worsening of these behaviors
- Three key subscales can suggest a possibility of particular psychiatric conditions:
  - **Irritability** – depression, bipolar disorder, ADHD, PTSD
  - **Lethargy** – depression
  - **Hyperactivity-Noncompliance** – depression, bipolar disorder, ADHD

ABC issues

- It captures "behavioral" data and does not capture much about the individual in other ways
- Some language on the pink sheet is not "modern" and you might explain this to the informant
- Despite its limitations it is the most useful and important rating scale for ID

How Does START Use the ABC?

- Provides a baseline initially
- Utilized quarterly, provides a longitudinal perspective of behavioral issues
- Used in combination with other data, can provide useful information about service needs

Other Factors

- Family Stressors (illness, loss of job, divorce, etc)
- Changes in caregiver
- Change in living situation
- Medications
- Change in day services
- Utilization of planned respite
- Medical Issues

Two Case Studies Illustrating Effective Use of ABC

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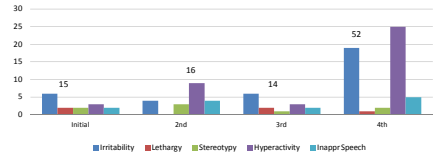
Case 1: John - 25 y-o male

Diagnosis: Schizophrenia, Paranoid Type and Mild ID

	Initial	2nd	3rd	4th
Irritability	10	0	6	19
Lethargy	8	0	2	1
Stereotypy	2	3	1	2
Hyperactivity-Noncompliance	16	9	3	25
Inappropriate Speech	5	4	2	5

ABC Results



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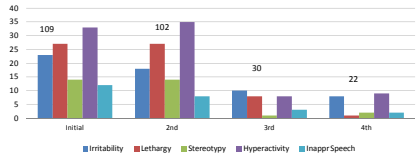
Case 1: Missy - 24 y-o female

Diagnosis: Autism, Mild ID, and Jacobsen Syndrome

	Initial	2nd	3rd	4th
Irritability	23	18	10	8
Lethargy	27	27	8	1
Stereotypy	14	14	1	2
Hyperactivity-Noncompliance	33	35	8	9
Inappropriate Speech	12	8	3	2

ABC Results



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Medication Side Effects and Monitoring

Anne Desnoyers Hurley, Ph.D.
University of New Hampshire-IOD

Denise Hall, LCSW
Virginia START Director, Region III

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The New York Times

Getting Too Many Antipsychotics

Many group-home residents with mental retardation are receiving psychotropic medications that may be doing far more harm than good.

MAIA SZALAVITZ 2011

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Major Issues

Issue:

High rate that medicines, particularly antipsychotics, are prescribed for **challenging behavior**

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Major Issues

Solution:

Empower support carers and families to monitor and discuss side effects in decision-making about the efficacy of medicines

Antipsychotic Medication USA General Population

- 2008 Domino & Swartz USA
  - (1997) 0.72%
  - (2005) 1.17%

Antipsychotic ID Studies

Tsiouris et al. 2013 NY State	45%
de Kuijper 2010 Netherlands	32%
Holden & Gitlesen 2004 Norway	31.6%
Lott *et al*. 2004 California	32%
Spreat 2000 *et al* Oklahoma	20.8%
Robertson *et al* 2000 UK	56/27/17%
Branford et al. 1995 UK	44%/13%
Jacobson 1988 NY	39.9/24.8/10.1%
Intagliata & Rinck, 1985 Missouri	45/29%

Side Effects (Adverse Events) Monitoring

- Performed by physician
- Conversation with patient
  - (self-report)
- Examination
- Studies & laboratory tests
- Specific exams (AIMS) takes extra time
- Most people with ID cannot inform well

Studies ID in UK audit side effects monitoring Metabolic Syndrome

- **Tin *et al*. 200**8, 185 SGA majority-- no MS significant monitoring
- **Patton *et al.* 2011**, 2,319 pts-- 40% no evidence of MS monitoring
- **Griffithes *et al*, 201**0, 178 pts
  - No reference to side effects 30%
  - Only MS monitoring was weight for 60%

Matson Evaluation of Drug Side Effects (MEDS)

Matson & Baglio 1998

- **MEDS:** 90-item *informant-interview* scale: chart review also necessary
- Severity and duration the last 2 weeks
- 3- point scale *(severity*: 0 = no problem, 1 mild/moderate, 2 severe/profound)and (*duration*: less, 1 mon., 1 month year, more than 1 year)
- Inter-rater reliability 0.85 & internal consistency 0.99, test-retest 0.76 (Matson, Mayville, Bielecki, Barnes, Bamburg, & Baglio, 1998).

START Medication Side Effects Project

- MEDS administered to all guest at the START Center programs
- Information shared with family, referral source, GP and psychiatrist
- Training for all staff on medications and side effects
- We are starting a conversation about efficacy and side-effects (informed consent)

MEDS Matson & Baglio 1998

9 categories, each 5-14 symptoms

(1) cardiovascular and hematological
(2) gastrointestinal
(3) endocrine/genitourinary
(4) eye/ear/nose/throat
(5) skin/allergies/temperature
(6) CNS-general
(7) CNS-dystonia
(8) CNS-parkinsonism/dyskinesia
(9) CNS-behavior/akathisia

MEDS (Matson & Baglio, 1988) Cardiovascular Subscale

1. A sudden loss of strength or fainting
2. Trouble breathing or shortness of breath
3. Rapid breathing (tachypnea)
4. Chest pain
5. Irregularity of the heartbeat
6. Abnormal frequency of heartbeat (Circle one: bradycardia / tachycardia)
7. Subnormal arterial blood pressure (hypotension)
8. Persistent high blood pressure (hypertension)
9. Abnormality in white blood cell count

Case Study: Jim

- 58 year old Male
- Diagnosed with Schizophrenia, Paranoid Type, Mild ID
- Placed in special education classes in first grade both expressive and receptive delays.
- Family marital conflict and alcoholism
- Lived at home until sister moved out
- First hospitalization at the age of 31 (3 yrs), poor sleep & appetite, agitation, anxiety, suicidal ideation diagnosed with schizophrenia, paranoid type
- Lived in ALF 20+ yrs closed due to violations
- Moved into current GH almost 2 years ago

Jim's Medications

Quetiapine	100 mg
Levothyroxine	150
Risperidone	2 mg bid
Benztropine	5 bid
Clonazepam	4 tid
Ranitidine	50 bid
Antacid	500 tid
Divalproex sod	125 tid
Buproprion SR	150 mg bid
Alprazolam	0.5 tid

Jim's Medical Problems

- Hypothyroidism
- Kidney disease
- Hypertension
- GERD
- Weight
- Tardive Dyskinesia
- Severe hearing loss in his left ear

Matson Evaluation of Drug Side Effects (MEDS)

Study compared to controls		**Norm**	**Jim**
(1) cardio /hematological		0.7	2
(2) gastrointestinal		0.13	3
(3) endocrine/genitourinary		0.0	2
(4) eye/ear/nose/throat		0.4	5
(5) skin/allergies/temperature		0.13	3
(6) CNS-general	0.87	22	
(7) CNS-dystonia		0.0	1
(8) CNS-parkinsonism/dyskinesia		0.33	11
(9) CNS-behavior/akathisia		0.14	4
TOTAL		**2.7**	**53**

Rogers vs. Okin 1975
MEDICAL LAW-THE RIGHT TO REFUSE ANTIPSYCHOTIC DRUG TREATMENT: SUBSTANTIVE RIGHTS AND PROCEDURAL GUIDELINES IN *MASSACHUSETTS*
***Rogers v. Commissioner of the Mental Health Department*, 390 Mass. 489, 458 N.E.2d 308 (1983)**

Contacts

- Anne Desnoyers Hurley
  - anne.hurley@unh.edu
  - hurleyannd@aol.com
- Denise Hall
  - DHall@nrvcs.org
- Johnny Matson - MEDS
  - johnmatson@aol.com

Emergency Assessments

Michelle Kluttz, BS
NC START West, Director

James Vann, MHP
VA START Region 1, Director

Calls Initiate Screening

Get there as soon as possible!

Partnerships are built by actual follow-through

Sometimes what is asked for isn't what is needed

Different assessment tools available

Assessment Tools (see handouts)

- Crisis assessment form:
  - Talk to the individual and to people who know the individual to obtain information
  - Speak with hospital/crisis personnel to get different perspectives
  - Obtain as much information as possible

Assessment Tools (cont.)

- Recent Stressors Questionnaire (RSQ)
  - Helpful in determining what is going on with the person by looking at different issues the person has encountered
  - Should be completed with someone who knows the person well in order to obtain accurate information
  - Completed at times of crisis and intake and repeated at 6 month intervals

Things to Consider

- Look at the presenting problem (why did you receive phone call?)
- Find out what happened recently:
  - A. Psychosocial (moves, changes in routine, loss, changes in staff, family, work/school)
  - B. Medication changes (increase/decrease/discontinuation/addition)
  - C. Medical issues (recent treatments, doctor visits, pain?)
  - D. Residential issues

Things to Consider (continued)

E. Duration of current problem

F. Diagnosis

G. Find out why caller thinks this happened, why now?

H. When was the last time individual was doing well and what does that look like?

Determining Disposition

- Talk to someone who knows the individual
- Find out at least 3 things the person enjoys doing (things that make person happy)
- What are some of the person's favorite foods
- Assess level of stability/risk (what can we do to create stability?)
  - A. Find out what usually works to calm person.
  - B. Is it achievable?
  - C. What resources are needed if any?

Determining Disposition (continued)

- Look at intensity/predictability/support needs (level of dangerousness, what does person typically do when he/she gets upset)
- Find out if PRN's have ever been tried and effectiveness
- What will the contract for safety look like? (between START and caregiver, between START Clinical and START Resource Center/in home supports team)
- Promote what works for the individual, while decreasing risk (if not stable to get to respite today, what plan can be established if any?)
- Process more, being proactive and not reactive

The Curious case of Barbie Button

Initial Contact:

START received the call around 6:00pm from a local hospital emergency department requesting a respite bed for Barbie whom had been brought to the ER two days in a row for appearing lethargic and refusing to take care of her personal needs. The ER staff stated that Barbie appeared medically stable, however the provider staff refused to take the person home. The staff were informed that the START Coordinator was on the way and would complete an assessment to help determine what could be done to resolve the situation.

The Curious case of Barbie Button

Thoughts on the way:

The hospital reports that Barbie is not presenting with any behavior concerns and has been medically cleared to leave.

Why is the staff refusing to take her home?

What was the reason for taking her to the hospital?

What does the provider feel is necessary to give them security concerning Barbie returning home?

Assessing Barbie

START's client is the system. The Crisis Assessment has to include the needs of all parties involved. You must identify the support needs of each part of the system in order to determine appropriate actions

Providing support:

Who needs support?

1. Barbie –
2. Provider –
3. Hospital –

Assessing Barbie

Supporting the system:

1. What are the hospital's concerns/needs?
2. What are the Provider's concerns/needs?
3. What are Barbie's concerns/needs?

Assessing Barbie

What's the whole story?

•Barbie lives in an independent home with her husband. She receives service supports during the day to assist with budgeting and job support.

•She had a major shift in presentation. In the span of about one week Barbie stopped getting out of bed, eating, participating in activities.

•Barbie saw her psychiatrist for a medication change

Advocating for Barbie

What is the best course of action?

•Make sure all parties have all of the information.

•Rule out possible reasons for such a quick shift in presentation.

•Provide continued on-site support while the answers are being found to give comfort to all parties that you are there to help.

Disposition

What's the answer?

After additional information was provided to the ER staff concerning the medication change one week prior, they agreed to run a blood test to determine lithium level. Barbie was found to be at a toxic level.

Barbie was admitted to the hospital on a medical unit for a few days for treatment. She has since returned home and has returned to her former self.

Data Collection and Reporting at the START Therapeutic Resource (Respite) Center

Andrea Caoili, LCSW
NC START East, Clinical Director

Steve Tuzo, BS
NC START East Respite Director

Overview of START Therapeutic Resource (Respite) Services

- START Therapeutic Resources (Respite) Centers provide:
  - Center-based planned support services
  - Center-based emergency support services
  - in-home support services

Overview of START Therapeutic Resource (Respite) Services

- Use a person-centered approach to assess and promote positive outcomes.
- Goals:
  - Provide comprehensive assessment
  - Systemic supports and services
  - Provide these supports in order for the person to return successfully and remain in their home.

Targeted Therapeutic Topics

- Social skills
- Mindfulness
- Self-esteem
- Coping with stress
- Independence
- Enjoyment

Comprehensive Assessment provided at the START Resource (Respite) Center

- Focus is on clinical and functional presentation
- Provides a basis for determining what services are needed, changes that are needed in the environment and/or training needs that should be pursued.
- The methods used depend on the presenting issues and incorporates all aspects of the person's life.
  - Use a bio-psycho-social approach to assessment, data collection and treatment

Biological

- Identification of observable signs of symptom presentation through the tracking of:
  - Eating patterns
  - Daily sleep log
  - Bowel movement charting
  - Completion of the MEDS

Psychological

- Systemic, direct observation in the environment
  - Behavior Tracking
  - Aberrant Behavior Checklist
- Tracking of daily functioning at baseline
- Tracking the occurrence of identified target behavior
- Diagnostic and treatment formulation based on the data collected

Social/Systemic

- Interactions with others while at the START Therapeutic Resource (Respite) Center through objective data collection following therapeutic group activities
  - Therapeutic Group Participation Document
    - Length of time in which the person participates
    - The level of participation in the therapeutic group

Why Data Collection is Important

- Assists with identification of trends in challenging behavior
- Concrete, objective symptom tracking to guide diagnostic and treatment formulations
- Track the effectiveness of therapeutic interventions.
- Assist with generalizing interventions to other settings.

Why Data Collection is Important

- Guides the development of the START Cross Systems Crisis Intervention and Prevention Plan
  - Bio-psycho-social vulnerabilities
  - Early warning signs of stress
  - Specific triggers
  - Prescriptive interventions to assist with crisis prevention and de-escalation

Case Study

- Initials: AM Age: 24 Male

Current Working Diagnoses:
Axis I: Autistic Disorder
Axis II: Mild Intellectual Disability
Axis III: High cholesterol
Axis IV: Environmental stressors
Axis V: GAF 39

Chief complaint:

- Interventions such as taking walks in the neighborhood, that have previously been successful for at home are not longer accessible. Because of this, AM has become aggressive with his neighbors and destroyed property in their lawn. These episodes occur with low frequency but are of high intensity and the police intervened in the most recent incident.

Purpose of respite stay:

- Provide observation, data collection and assessment of symptoms of anxiety
- Identify interventions AM can use at home to assist with reducing anxiety.

Handouts

- Behavior Tracking Data Sheet
- Sleep log
- BM tracking log
- Therapeutic group note

Observed Symptoms of Anxiety

- Vegetative functioning was at baseline: sleep and eating patterns were not disrupted when AM experienced anxiety
- Repeated requests to go for a walk
- Repeated statements such as "go home", "I want to go home", "not going to stay no more nights", "go home today"
- Request to take several showers per day

Symptoms, continued

- Pacing and talking to himself—increase in frequency and intensity of pacing
- Repeated requests to play basketball
- Self-stimulating 'rocking' stops
- Repeated statement 'I'm ok, I'm ok'
- Over 1 hour spent isolated in his room
- The use of verbal communication decreases or there is a decrease in the amount of phrases he uses

Coping Skills and Interventions Identified

- Responded well to a sensory diet with sensory activities scheduled throughout the day:
  - Listening to music on his portable CD player
  - Playing basketball
  - Body wrapping
  - Walks in the community-at least 3 walks per day
  - Swinging on swings at park
  - Use of "sensory pack" when in the community

Interventions, continued

- Spending time alone in his bedroom
- Deep breathing
- Breaking down requests to smaller and concrete concepts no more then three steps.
- When observing symptoms of anxiety, give AM 3-4 minutes to process what is being asked of him.
- Recognize and understand AM's verbal communication
  - "I'm alright"
  - Provide reassurance
- Use first _____, then _____ language.
- AM should always know what the next scheduled activity is.

What do you do with all this data?

- Training and support of caregivers to ensure interventions were generalized to his home environment
  - Utilize daily picture schedule for AM. Review it in the morning and afternoon.
  - Schedule should include sensory activities including taking walks, exercise, swinging, body wrapping
  - Bring sensory pack with AM on all outings. Include his portable CD player, a crunchy snack, sensory manipulatives, sunglasses

Development of the CSCP

- The START CSCP was developed and all signs of anxiety were outlined as well as prescriptive interventions to reduce anxiety.
  - If AM asks to take a walk, be sure he is able to do so.
  - AM needs to be given the opportunity to make decisions as to what he will do next. He should be given several activities to choose from and should not be told that he has to do a particular activity.
  - AM should be given at least 1 minute to process all requests. If showing early warning signs of anxiety, he will need longer (up to 3-4 minutes)

Additional Assessments/Services Identified:

- Communication Assessment: continue to develop ways for AM to communicate needs with less reliance on verbal means
- Occupational therapy assessment and evaluation: further identify and practice interventions used to reduce sensory dysregulation
- Continued outreach/support provided for AM and his family by the START Coordinator
- In-home supports: assist AM and family with generalizing skills/interventions learned at the START Center
- Advocacy for the family to assist with filling of service gaps

Questions/Comments
Thank you!