She Wants to Have a Baby:

Teaching Individuals with
Developmental Disabilities
Infant-Care Skills
Through the Use of
Infant Simulation
and Self-Management

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The Arc
Ulster-Greene
NYSARC, Inc.

About Us

- Agency serving individuals with developmental disabilities of all ages
    - Educational Supports for school-age children and adolescents
    - Pre-vocational/Vocational Services
    - Residential Services
    - Service Coordination
    - Community and Recreational Services
    - Day Programming
    - Clinical and Behavioral Services
- Mission: *To offer people with intellectual and other developmental disabilities opportunities to live and experience full lives*

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About Us

- Ulster Rehab Clinic
  - Behavioral Health Services- Psychology & Social Work
  - Physical Therapy
  - Occupational Therapy
  - Speech and Language Pathology
  - Rehabilitation Counseling
  - Treatment Coordination Services

ASHA DISCLOSURE STATEMENT

- **Financial:** Both Presenters are employees of *the Arc of Ulster Greene* and receive salaries.

- **Non-financial:** Nothing to report

Agenda

- History of Sexuality for ID/DD population
- Changing Perspectives
- Parenting & DD Population
- Status of Research
- Real Care Baby Program
- Case Studies
- Demonstration
- Where do we go from here?

Brief History of Sexuality for the DD Population

- 1880-1940 Eugenics Movement:
  - Forced mass Sterilization
  - Segregation
- 1940's -1960's Denial and Suppression
- 1960's-on Civil Rights movement:
  - Sexual revolution
  - Normalization and deinstitutionalization
- Continued stereotypes
- Understanding, empowerment, training, education

(Kempton & Kahn, 1991; Lightfoot & LaLiberte, 2011)

Today's Status

- Sexuality Assessment
- Determination of consenting or nonconsenting
- Education
- Social groups
- Sexuality is more of a focus, but what about parenting?

Deciding to Parent

- Increasing number deciding to exercise the right to conceive and become a parent

- Historically limited supports for parents with intellectual disabilities

- Courts often focus on a parent's disability, rather than their behavior (Lightfoot & LaLiberte, 2011)

- Stage of denial: Most agencies are not prepared to provide pregnancy education, infant-care skills, etc.

- Most agencies do not provide services for an individual's baby within certified cites

- What if they don't have the skills and/or resources?

- Where and what are the support services? Child care skills training?

- Services are needed!

Status of Research on Parent Education

- Parenting skills is behavior!
  - Negative reinforcement (Thompson, Bruzek, & Cotnoir-Bichelman, 2011)
- Components of successful child care skills training for adults with Developmental Disabilities
  - **Instruction, Self-Instruction, & Pictorial Cues** (Feldman & Case, 1997; Feldman, Ducharme, Case, 1999; Feldman & Case, 1999; Feldman, 2004)
  - **Modeling, Feedback, and Reinforcement Schedules** (Feldman, Ducharme, Case, 1999)

Status of Research on Parent Education

- Behavioral Skills Training (BST) (consisting of modeling, rehearsal, and feedback)

- BST used to improve caregiving skills across time and context (typically developing adults) (Miles & Wilder, 2009)

- Limitations of some studies on the topic:
    - Limit funds to design interventions
    - Focus on preference or other variables, rather than behavior
    - Self-report measures

- Research is needed!

RealCare Baby Program

- RealCare Baby simulators are intended to mimic some of behavior of newborn babies (crying to be fed, burped, rocked, or changed; cooing when successful)

- Software tracks and reports on caregiving actions and mishandling; also tracks surrounding temperatures, time in a car seat, & clothing changes

- Intended as a means of teen pregnancy prevention, skill development, child abuse prevention

- MORE AT: www.RealityWorks.com

Research on Infant Simulators

- Focus on pregnancy prevention rather than parenting skills (Brinkman et al., 2010)

- Focus on expectations, perceptions, attitudes, and beliefs (Out & Lafreniere, 2001; Somers & Fahlman, 2001; Strachan & Gorey, 1997)

- Mixed reviews... Limited effectiveness at changing adolescent safe sex practices (Somers & Fahlman, 2001)

- BUT Infant simulators paired with competency based training were effective at improving childcare skills (for typically developing adolescents) (Roberts & McCowan, 2004)

- More research is needed looking at the different applications of this for different populations

Case Study 1 - Jill

- Mild Intellectual Disability
- Not participating in Day Hab, Pathways, counseling, or much else
- Loved children, especially babies
- Aspired to get a job in a day care

Jill's Participation

- Introduced the RealCare program

- Modifications

- Task Analyses

- Started with paper diaries

Task Analysis for Changing a Diaper

1. When baby starts to cry, swipe bracelet over chest until you hear a chime.

2. Take a peek inside the back of the diaper to see what color is on the inside of the diaper.

3. Lay baby down on a flat surface.

4. If the baby has a diaper with a green square on it, get a diaper that has a yellow square out of the diaper bag. If the old diaper has a yellow square on it, get out a diaper with a green square.

5. Remove baby's bottoms.

6. Gently lift baby's legs and place new diaper under baby (with old diaper still on).

7. Undo the velcro on the old diaper baby is wearing.

8. Gently lift baby's legs and remove old diaper. Leave new diaper in place under baby's bottom.

9. Bring front of new diaper up between baby's legs.

10. Fasten the Velcro on each side of diaper.

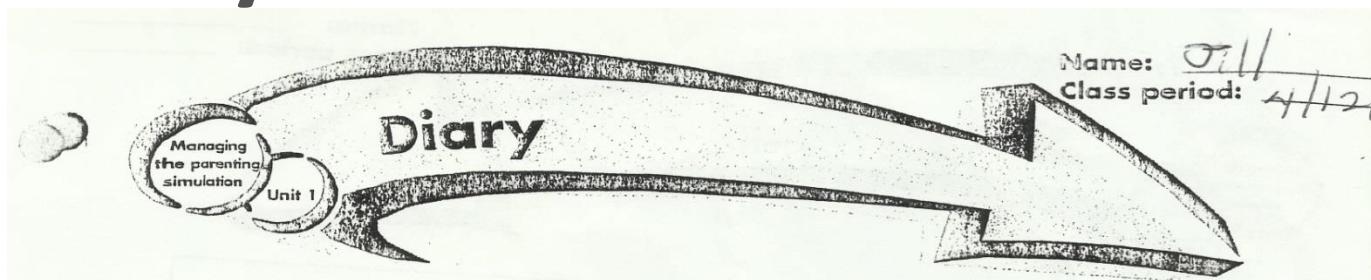11. Put bottoms back on baby.

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RealCare Diary

Diary

Managing the parenting simulation
Unit 1

2/17/16
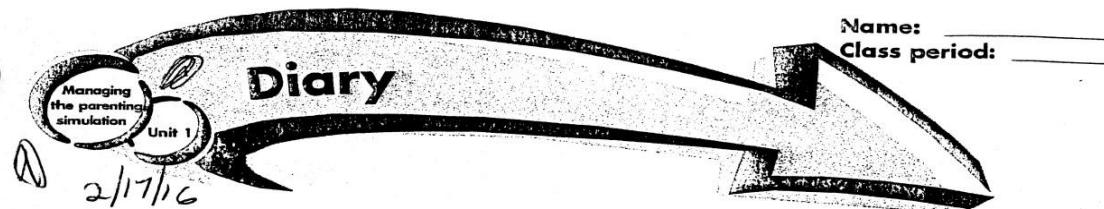
Start time	End time	Care required	Other	Comments
5:23	5:35	feed		
5:35	5:46	burp		
5:46	5:49	change		
6:25	6:37	feed		
6:37	8:46	burp		
8:48	8:50	change		
2:00	2:08	change		
2:12	2:27	feed		
2:27	2:34	burp		
2:34	2:36	change		
4:50	4:55	feed		
4:55	5:00	burp		
6:10	6:18	rock		
7:10	7:17	change		
7:18	7:26	feed		
9:05	9:10	feed		
10:30	10:48	rock		
11:00	11:11	Burp		
11:39	11:41	change		
1:22	1:26	feed		
1:26	1:30	burp		
1:30	1:34	change		
3:15	3:21	change		
2:50	2:54	change		

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Diary with Self-Reinforcement

Managing the parenting simulation — Unit 1

Diary

Name: Jill
Class period: 4/12

Start time	End time	Care required	Other	Comments
11:15	11:30	Feed		Good job! Good job Staying calm!
11:30	11:31	burp		
11:31	11:32	change		
11:32	11:46	feed		good
12:0	12:05	im clean + chram and came quiet		
12:53	1:02	feed		good
1:02	1:06	burp		good job + slow
1:06	1:08	change		good job + slow
1:08	1:23	feed		good Job + slow
2:05	2:17	burp rock		good job
2:05	3:17	feed		good job
3:17	3:26	BURP		great job.
3:26	3:30	feed		great Job

Disadvantages of Paper Diaries

- Inconvenient and cumbersome

- Papers would get lost or mangled

- Low acceptability rating – not at all enjoyable

RealCare Task Analysis

RealCare® Parenting Program
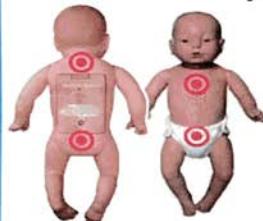
Student Care Card

real care

You do not have to touch your ID to Baby's back.
You will hear a chime sound if Baby recognizes your ID.
The best areas for ID recognition are shown below.

When Baby starts crying:

Step 1: **Pick Baby up and listen for the chime sound.**
If Baby chimes, that means it recognizes you as the parent.
First try feeding, burping, rocking, or changing diapers.

- *Feed: Hold the bottle or breastfeeding device to Baby's mouth. Baby makes feeding sounds and coos when done. Hold Baby while feeding or Baby cries.*
- *Burp: Pat Baby's back. Baby makes small whimpering sounds and then burps after several minutes.*
- *Rock: Provide constant, gentle rocking motion. Baby makes soft whimpering sounds and coos when done.*
- *Diaper: Take Baby's diaper off. Baby still whimpers. Put the OTHER diaper on. Baby coos.*

If you heard the chime and Baby is still crying:

Step 2: **Pick Baby up and try rocking for 1 minute.**
Baby's head may have been unsupported, it may have been roughly handled, or Baby may just be fussy. Rocking helps Baby quiet down.
Fussy crying lasts for 3 MINUTES and then Baby coos.

If you did not hear the chime and Baby is still crying:

Step 3: **Double-check the ID.**
Hold your ID next to Baby's diaper area and listen for the chime again. If Baby still does not chime, make sure Baby is being held on its back.

Here are some other things that may happen while you have Baby:

- Breathing sounds mean Baby is sleeping or being rocked.
- Coughing or cooing (happy) sounds means Baby is awake.
- Hearing the ID chime but not being able to quiet Baby for a few minutes means Baby was just fussy.
- Baby cries if it is upside down or on its tummy for five or more seconds.
- If you are feeding, burping, rocking, or changing Baby when the head falls back or you roughly handle Baby, Baby cries loudly. Rock Baby until it is quiet. You don't need to care for Baby until it cries again.
- You have 2 minutes to start caring for Baby before missed care is recorded.

Frustration-reducing measures for when Baby is crying

- Take several deep breaths and count to ten.
- Say the alphabet.
- Put Baby in a safe place, then leave the room for a few minutes.
- Close your eyes and think of something pleasant.
- Ask someone else to help.

RealCare® Baby II records Shaken Baby Syndrome if it is shaken (head moves back, forward, and back again in two seconds).

Safe holding methods

At your shoulder | The cradle hold | The football hold | Using a carrier

IMPORTANT SAFETY REMINDERS!

- Baby may cry while you are driving. Please be aware that the crying may start unexpectedly, and you should be prepared.
- Never leave Baby unattended in a public place given the potential for misunderstanding.
- Bring your vehicle to a complete stop in a safe location before caring for Baby, or to retrieve a piece of Baby's equipment that falls.
- Do not feed, burp, rock, change diapers, or otherwise care for Baby while driving.
- Failure to install Baby in a car seat in a motor vehicle could result in Baby or the seat becoming projectiles in the event of a sudden stop or accident.
- Do not place Baby on or near a stove, especially while cooking.
- Never take your wristband off. Not only will you be deducted points, but you may lose the ID or stumble around in the dark looking for it if Baby cries during the night.
- Baby should sleep somewhere close to your sleeping quarters, but not in bed with you. Baby may fall out of the bed or you could roll over on it, causing damage to Baby and discomfort to you.
- Loud crying near people with potentially serious physical conditions, such as those susceptible to heart attack or stroke, should be avoided.
- Make a note in your diary where you had to delay care of Baby because your safety or that of others may have been compromised.
- Do not place Baby in or near water.
- Baby's crying or other sounds may cause pets to become agitated or aggressive. Keep Baby out of the reach of pets or other animals.
- Use an infant car seat or carrier to transport Baby rather than holding Baby at all times.
- Baby weighs 6.5 to 7 pounds and could cause discomfort for individuals with back pain.
- Do not operate any type of equipment or attempt tasks requiring the use of both hands while holding Baby.
- Do not allow small children to play with Baby. Baby's hands and feet could be a choking hazard.

Realityworks
Live it. Learn it.

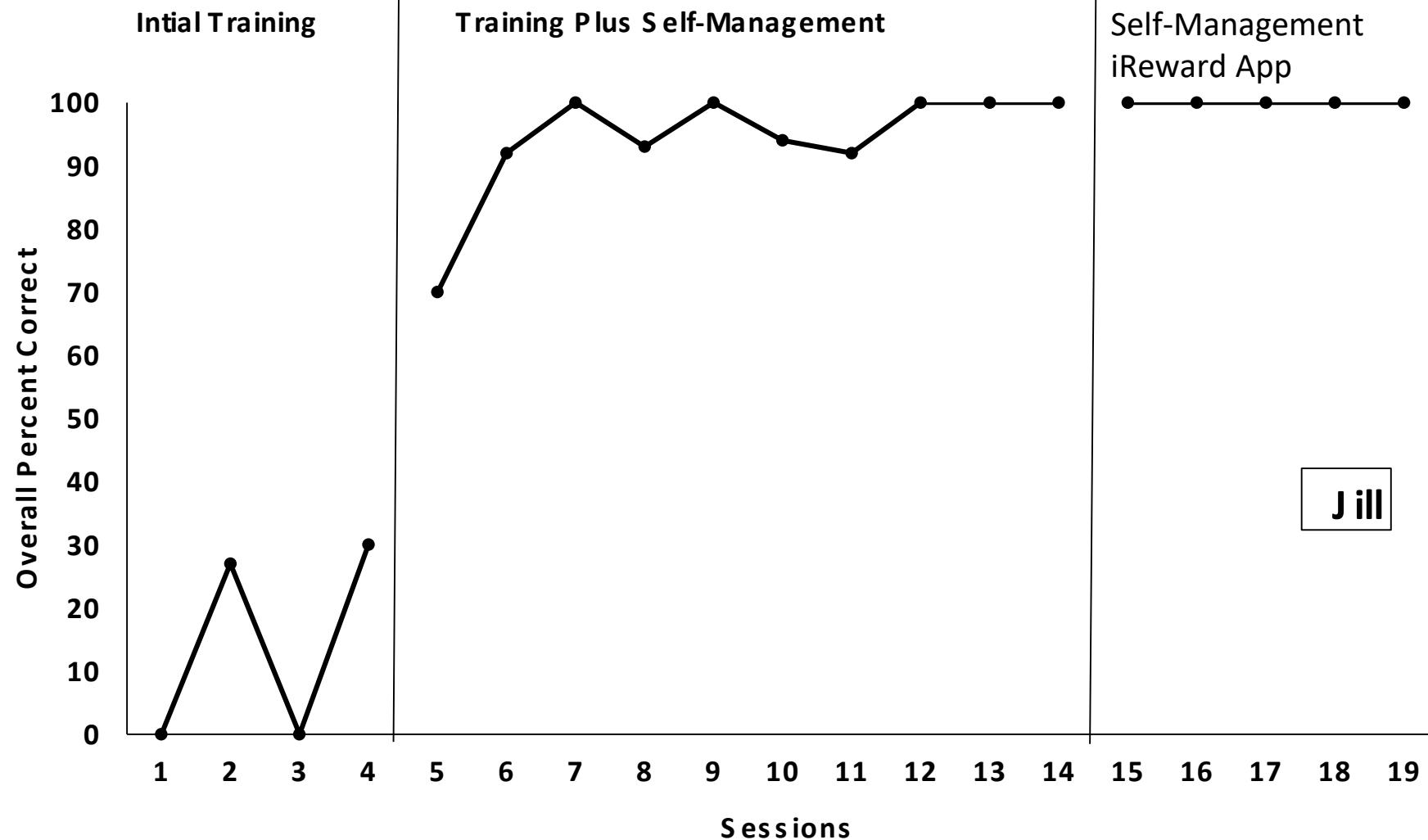D930

Jill's Participation

- Provided the iRewards app

- Positive acceptability feedback

- Program became very enjoyable

- Began to incorporate Premack Principle

- Participation in Day Hab and Pathways improved

iReward Phone App

Jill's Chart

This week (70)

Sun 08/28	Mon 08/29	Tue 08/30	Wed 08/31	Thu 09/01	Fri 09/02	Sat 09/03

Burp Baby

| | ★ | ★ | 2 | 3 | 4 | |

Feed Baby

| | 5 | 6 | 4 | 7 | 6 | |

Change Diaper

| | 4 | 7 | 4 | 2 | 5 | |

Rock Baby

| | ★ | 2 | ★ | 3 | 2 | |

EDIT TASKS...

Jill's Data

Expanding Skills

- Goal of working in day care
- Worked with two babies at a time

Jill Continued to get 100%

RealCare® Baby Simulation Report

Class Babysitting 2

Student **ID1** 4AD54 **ID2** 00000

Baby **BABY4EBD** African American Female

Start 4/12/2016, 11 AM **Stop** 4/13/2016, 11 AM

Schedule Order 8 2 2 2 2

Quiet Times

Total Simulation Time: 0d 04h 27m   **Baby cried 6 minutes total**

Proper Care			Mishandle		
Rock	1/1	100%	Shaken Baby	0	0%
Diaper	2/2	100%	Head Support	0	0%
Burp	3/3	100%	Wrong Position	0	0%
Feed	6/6	100%	Rough Handling	0	0%
Average	12/12	100%	Other		0%
ID1 was used 13 times, ID2 was used 0 times			Total	0	0%

Performance Overview: 100%

Tuesday, April 12
11:10 AM Start Simulation
3:37 PM Stop

Instructor did not…

RealCare® Baby Simulation Report

Class	Babysitting 2
Student	instructor
Baby	
Start	3/8/2016, 11 AM
Schedule Order	12 12 12 11 11
Quiet Times	

ID1 00000	**ID2** 00000
BABY9073	Hispanic Male
Stop	3/8/2016, 12 PM

Total Simulation Time: 0d 00h 20m

Proper Care		
Rock	0/0	0%
Diaper	0/0	0%
Burp	0/1	0%
Feed	1/2	50%
Average	1/3	33%

ID1 was used 0 times, ID2 was used 0 times

Performance Overview: 30%

Baby cried 6 minutes total

Mishandle		
Shaken Baby	0	0%
Head Support	1	-3%
Wrong Position	0	0%
Rough Handling	0	0%
Other		0%
Total	1	-3%

Tuesday, March 8

11:10 AM	Start Simulation
11:14 AM	Missed Feeding
11:22 AM	Missed Burp
11:22 AM	Head Support
11:30 AM	Stop

Jill

- Graduated from the RealCare Program

- Incorporated fading

- Currently Job Hunting

Case Study 2 - Jackie

- Mild Intellectual Disability

- Had a part-time job

- Was considering parenthood & child-care jobs

Jackie's Participation

- Had great difficulty when baby cried

- Was overwhelmed with using pen/paper diary

- Decided parenthood was definitely *not* for her!
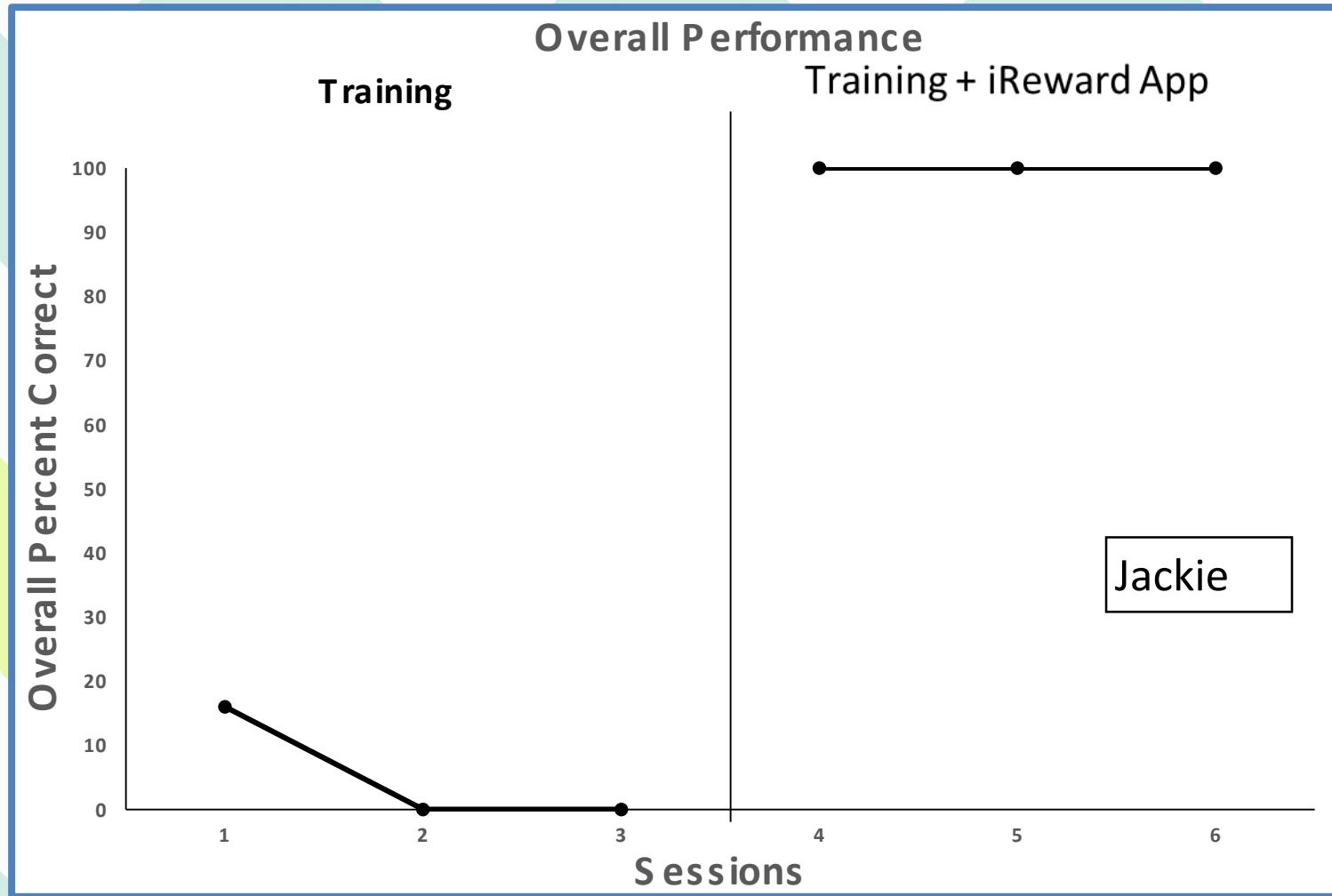
- Became very discouraged

Jackie

- Took a break for several weeks
- Offered iReward app
- Immediate progress –> 100%
- Confounding variable – competition with peer

Jackie's Data

Overall Performance

Training — Training + iReward App

Jackie

Overall Percent Correct (y-axis: 0–100)
Sessions (x-axis: 1–6)

Case Study 3 - Janine

- Mild Intellectual Disability
- Various mental health diagnoses
- Several psychotropic medications
- 4-bed group home
- Initially non-consenting, but became consenting

Janine - CTD

- Had a boyfriend
- Went on birth control
- And then…
- ICD 10 Diagnosis: Z33.1

She's Having a Baby!

- Z33.1 = "Pregnant State, Incidental"

Janine - CTD

- Went off all psychotropic meds
- Moved to another group home for her safety
- Team began planning

Janine - CTD

- Always had the dream of having a baby

- Wanted to keep and raise her own baby

- No skills, experience, or knowledge of raising babies

Janine - CTD

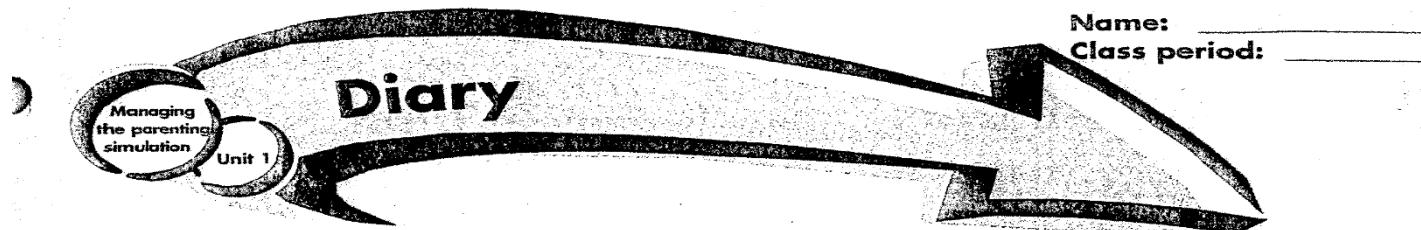- RealCare Baby curriculum
- Parenting classes
- Counseling

Janine's Progress

- Difficulty acquiring skills
- Disliked paper and pen diaries
- Loved her phone!

RealCare Diary

Diary

Managing the parenting simulation — Unit 1

Name: _____
Class period: _____

Start time	End time	Care required		Other	Comments

RealCare® Baby Simulation Report

real care

Class

Student **ID1** 4AD54 **ID2** 00000

Baby baby **BABY9073** Hispanic Male

Start 9/23/2015, 9 AM **Stop** 9/29/2015, 10 AM

Schedule Order 14 2 7 10 3

ABUSE SHUTDOWN

Quiet Times

Total Simulation Time: 1d 00h 24m

Proper Care		
Rock	0/0	0%
Diaper	7/10	70%
Burp	5/7	71%
Feed	9/12	75%
Average	21/29	72%

ID1 was used 49 times, ID2 was used 0 times

Baby cried 33 minutes total

Mishandle		
Shaken Baby	0	0%
Head Support	23	-69%
Wrong Position	2	-6%
Rough Handling	1	-3%
Other		0%
Total	26	-78%

Performance Overview: 0%

Wednesday, September 23

9:45 AM	Start Simulation
9:52 AM	Rough Handling
10:37 AM	Head Support
10:54 AM	Missed Feeding
10:54 AM	Head Support
11:34 AM	Missed Diaper
11:34 AM	Head Support
1:26 PM	Head Support
1:30 PM	Missed Diaper
4:40 PM	Head Support
6:49 PM	Missed Burp
6:49 PM	Head Support
10:44 PM	Missed Diaper
10:50 PM	Missed Feeding
10:50 PM	Head Support

Thursday, September 24

2:15 AM	Missed Burp

Thursday, September 24

2:16 AM	Head Support
8:36 AM	Head Support
8:39 AM	Head Support
9:08 AM	Missed Feeding
9:09 AM	Head Support
10:00 AM	Head Support
10:00 AM	Head Support
10:01 AM	Head Support
10:02 AM	Wrong Position
10:02 AM	Wrong Position
10:05 AM	Head Support
10:05 AM	Head Support
10:06 AM	Head Support
10:06 AM	Head Support
10:07 AM	Head Support
10:08 AM	Head Support
10:08 AM	Head Support
10:08 AM	Head Support

Thursday, September 24

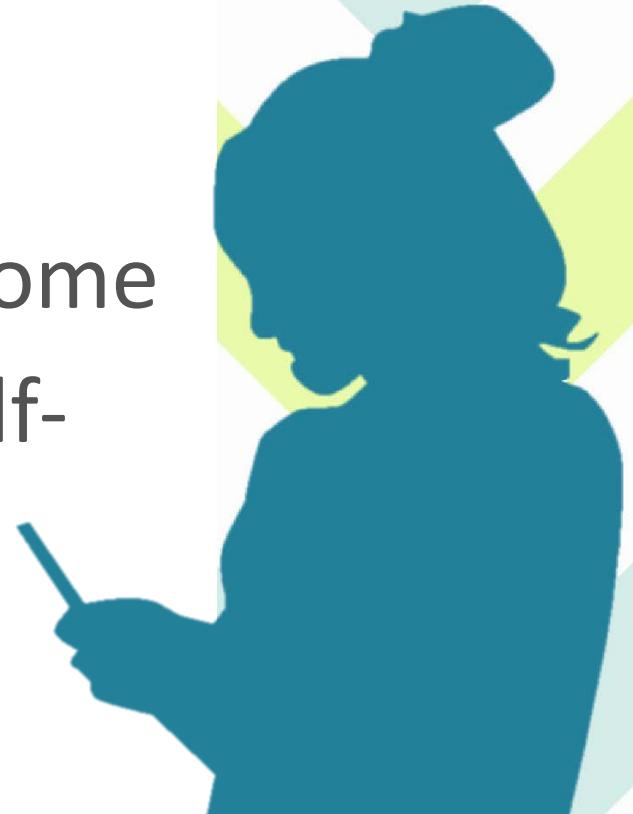|	
10:09 AM	Head Support
10:09 AM	Abuse Shutdown
10:09 AM	Stop

Comments:

Changes Made

- Increased training
- Intensive 1:1 training (BST), modeling, practice and feedback
- Office sessions, day hab, home
- Provided phone app for self-management
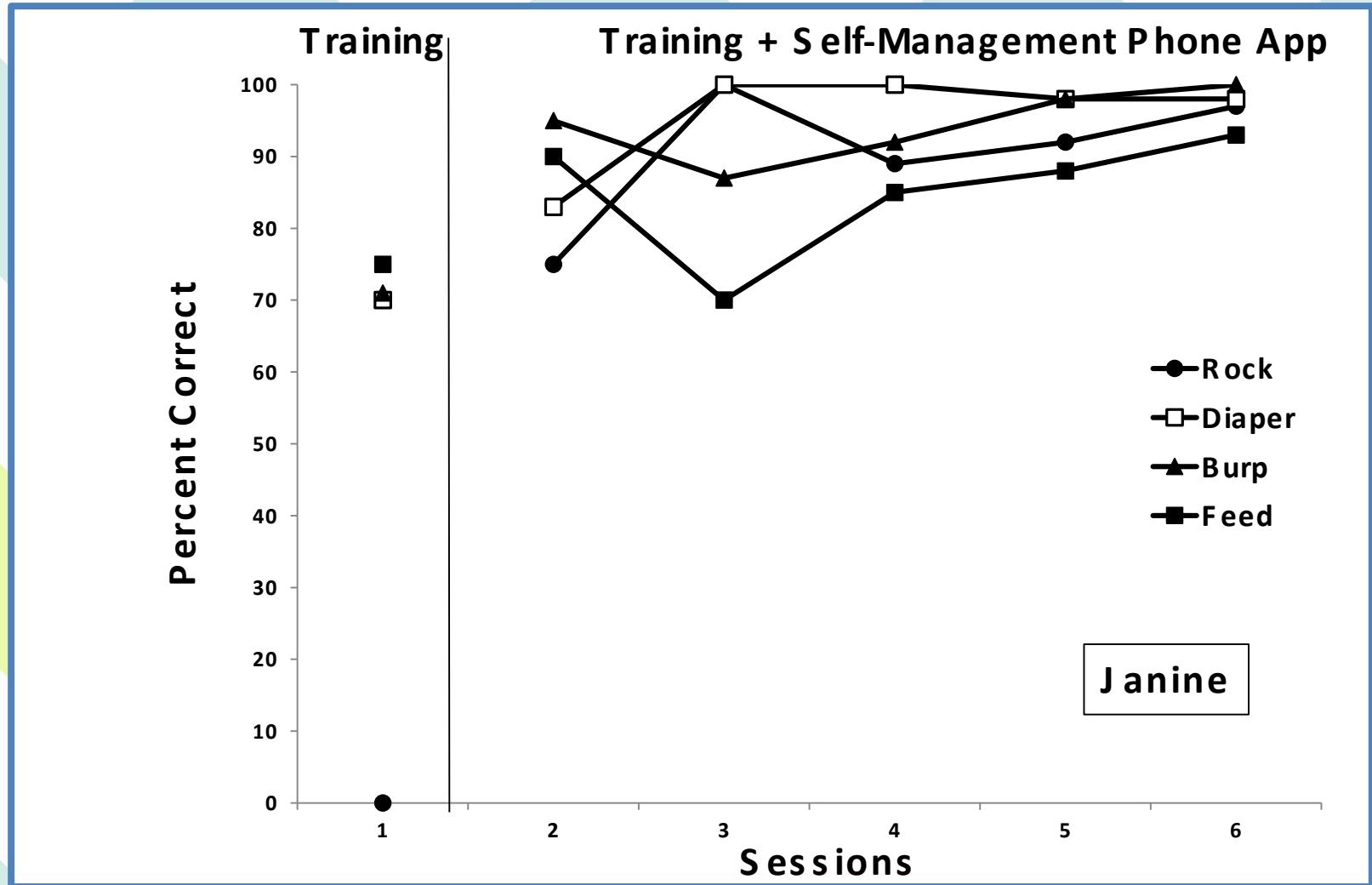
Chore Chart App

robot baby		# Prizes	1
		Change Stickers	

	Chore						
🪑	feed baby	N	M				❌
🍎	burp baby	T	I	M	M		❌
📦	rock baby	Y	M	V			❌
🪑	change diaper	A	Y	D	E	T	❌
🦆	support head	W	Y	H			❌

Janine's Data

Janine's Outcome

- Had a healthy baby boy

- Family stepped forward as an additional support

- Living with family members

- Mom, dad and baby are doing well!

Limitations

- Child care skills for older babies, children, and teens are not addressed

- Need generalization to real babies and real circumstances

- Multitude of factors come into play when parenting

- Cost of equipment: $500-$1000+

- Robot babies are not real babies!
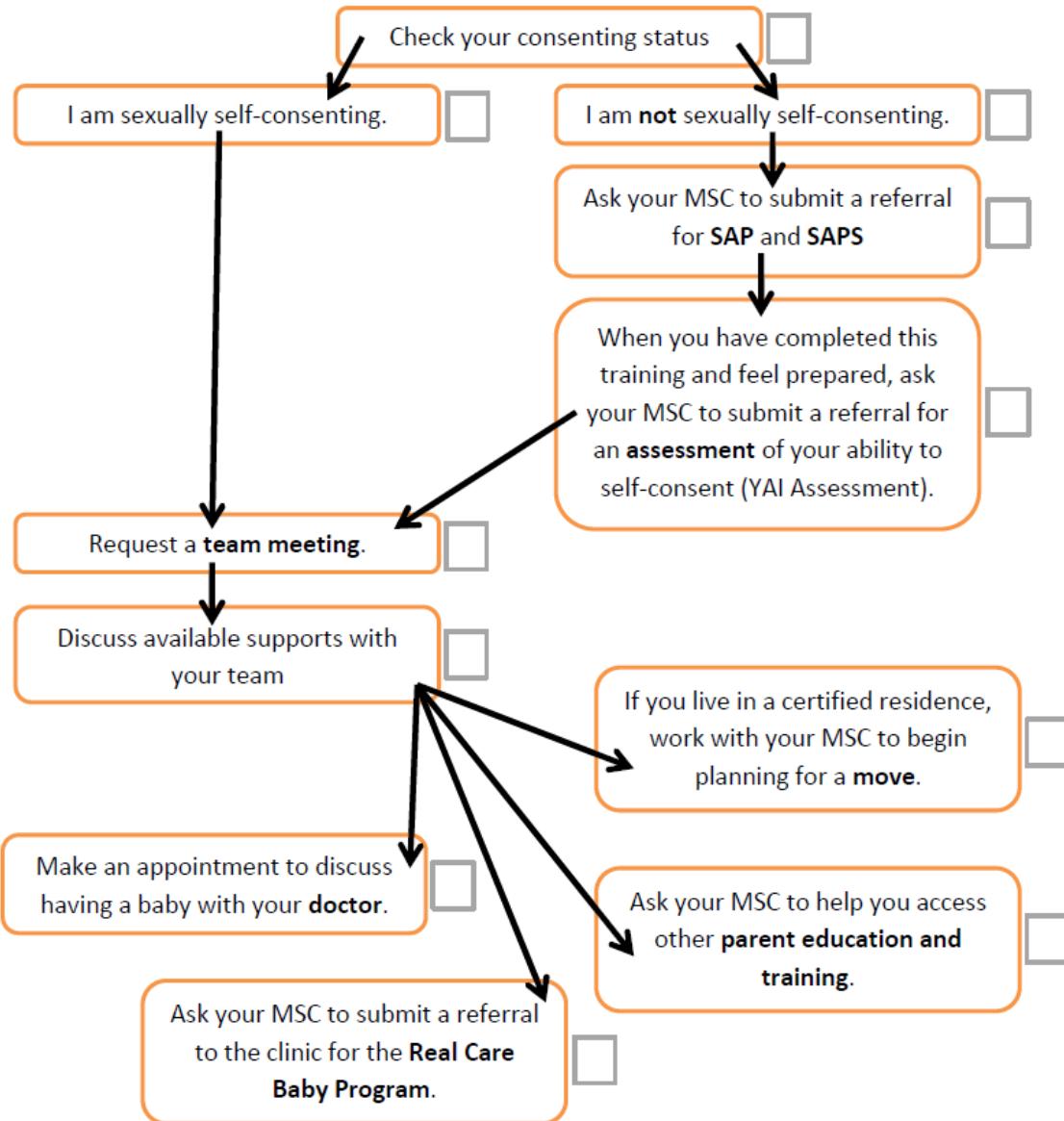
DEMONSTRATION

How Should We Handle the Issue?

- Need to have conversations early on
- Possibly incorporate as part of sexuality assessment or sex education
- Education and training should be provided before pregnancy
- Curriculums should be modified for various intellectual levels
- Need to consider supports

Preparing for Parenthood Checklist

Check your consenting status ☐

I am sexually self-consenting. ☐

I am **not** sexually self-consenting. ☐

Ask your MSC to submit a referral for **SAP** and **SAPS** ☐

When you have completed this training and feel prepared, ask your MSC to submit a referral for an **assessment** of your ability to self-consent (YAI Assessment). ☐

Request a **team meeting**. ☐

Discuss available supports with your team ☐

If you live in a certified residence, work with your MSC to begin planning for a **move**. ☐

Make an appointment to discuss having a baby with your **doctor**. ☐

Ask your MSC to help you access other **parent education and training**. ☐

Ask your MSC to submit a referral to the clinic for the **Real Care Baby Program**. ☐

Other Examples of Services

- United ARC; Positive Parenting
- **Individualized Parent Support** — Home-based parent skills training, case management, service advocacy and family support
- **Parent Education and Support Groups**
- **Supervised Visitation**
- **Intensive Structured Supported Family Living** — Apartment building; apartments available for families, and an adjacent apartment for an on-site supportive neighbor; Parent educators work with families
- **Consultation** — Training workshops and consultation.
- **Mentoring Support** — Family Friends volunteers are matched with families to provide support and guidance to both children and parents
- **Grandparent/Kinship Caregiver Support** — Networking, support groups and individualized home visits for grandparents and kinship caregivers with primary care giving responsibility for raising a grandchild or young relative

Where Do We Go From Here?

- Educate and Advocate!
- Plan proactively instead of reacting emergently
- Incorporate evidence-based strategies
- Incorporate appealing technology
  - Self-management apps
  - Infant simulators
- Practice needs to generalize to real babies
- Incorporate supports
- We need more research!

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