

A Families' Guide to Best of All Teenagers

**best of all (noun) \best of all\
is continual, measurable, celebrated and it never ends.**

*It is a daily challenge to do a little better than you did
the day before and it's always celebrated.*

*Possible manifestations: standing just one
second longer, reading just one more word,
learning just one new number, taking just one
more step, never a competition, never completed.*

GiGi's
Playhouse™

Down Syndrome Achievement Centers
educate. inspire. believe.



You can keep your child engaged in meaningful experiences as a teenager! And we'll help!

Our goal at GiGi's Playhouse is to celebrate every display of a learner's best of all! We do this through purposeful programs at our Playhouses that start at the prenatal stage and continue into adulthood. We build specific skills & focus on areas of development. For our teenagers, we specifically focus on social interactions and social skills, as well as gross motor skills and language and communication development.

GiGi's Playhouse is a place to develop independence and push boundaries. We understand that it may be challenging to keep your child active and engaged – but it is so important to keep him or her happy, healthy and confident!

This book is a tool for you! Our program leaders build social-based activities for your teen to participate in while at the Playhouse and to continue building these skills at home. We've provided many of our favorite activities in this book. Each activity is FUN, but very purposeful and learning based.

With your dedication and GiGi's Playhouse programs, your child will

- **Increase social skills**, focusing on group participation and increasing leisure activity options;
- **Increase speech and language development**, focusing on expanding the teen's communication skills and targeting social and pragmatic language skills in the context of the structured activities.
- **Prepare for career and volunteer opportunities**, focusing on professionalism, customer service skills and confidence;
- **Increase motor skills**, focusing on general health and wellness, strength, balance, and awareness of personal space; and
- **Receive academic support in literacy and/or math**; and
- Achieve his or her *Best of All!*



Building Best of All during programs at GiGi's Playhouse

It is important to foster independence and confidence in your child. Set high expectations every day – encourage the completion of daily tasks, meaningful interactions and participation in activities. The skills and knowledge that teenagers have may be lost if they aren't engaged in regular practice; in other words, if they don't use it, they'll lose it!

While your child participates in programs at GiGi's Playhouse independently, you continue to play a role in his or her development. Here's what you can do, as related to our programs –

- Encourage your child to attend our programs regularly.
- Be timely and accountable. Ensure your child arrives to programs on time, participates regularly and completes all take home activities or homework.
- GiGi's Playhouse encourages all teenagers to work out regularly and eat healthy – hold your child accountable to this while at home!
- Communicate with the staff and program leaders regularly. Together we are on the same team and all want your child to reach his or her greatest potential!
- Follow the rest of the tips within this book to practice and build skills at home!



Tips & Tools for *Best of All* at Home

We've provided a number of activities to do at home that are easy, take little time and are purposeful. Help your child build these activities into his or her everyday life and hold him or her accountable! The growth that you'll see will be amazing!

Build Social Skills

Social skills develop throughout one's life. This is what allows us to interact with others, form relationships and develop independence.

During the teenage years, many individuals with Down syndrome are working towards developing more mature communication and social skills throughout their daily environments. It is important to continue stimulating teenagers in social interactions, both to increase their independence and to practice and strengthen language skills.

Tips and activities to build social skill development:

- Ensure that your child has the opportunity for meaningful conversations daily. This could include shopping trips to the grocery store, dinner with friends, talking about current events or sending notes via email.
- Set a goal with your child each week. Keep track of your child's success during the week and celebrate together. As he or she achieves the goal, make it a bit more challenging the following week. Goals could include;
 - Conversations with friends or family via the phone or Skype
 - Greet friends with a hand shake and eye contact
 - Speak in complete sentences when addressing someone
 - Maintain eye contact during a conversation
 - Plan and serve dinner one night during the week
 - Read an article or watch a newscast – hold conversations regarding these current events
 - Get involved in neighborhood activities and attend regularly
 - Volunteer at a local soup kitchen, business or special event
 - Plan a family fun night – gather supplies, plan menu and shop
 - Create something or interest – a craft project, model of a car, take pictures, or more
 - Write a resume together and deliver it to potential employers
 - Practice interviewing together
 - Practice reading, writing and math regularly each week. Read recipes, count change and write grocery lists.

- Encourage your child to participate in group outings and events. By being in a social environment, your child will then be provided with many opportunities to engage with others. Get involved at a local animal shelter, recreational organizations, church groups or even health club.
- Role-play with your child before a big event. Practice greeting someone properly, maintaining conversation and responding to questions. This practice will greatly increase your child's confidence!
- If your child has difficulty navigating a conversation or understanding a situation, use social stories to provide clarity. Highlight social cues, events, feelings and reactions by revisiting the situation and actions. Use visual cues or role-playing to support understanding.
- It is often necessary for a family member or friend to be the facilitator during a group interaction. Draw each participant into the planning discussions, asking for their input or ideas and offering choices whenever possible.

Awareness of personal space is an important construct to facilitate appropriate social interactions. From a physical standpoint, developing an awareness of where an individual places his/her body and how to move through a variety of environments are skills to learn in this area.

Tips and activities to build awareness of personal space:

- When having conversations with the adult, model an appropriate distance for speaking.
- Teach your child to say "excuse me" or use a gesture when passing through a crowded area. After indicating their desire to pass, instruct your child to wait until space has been made before moving through the space. Practice this consistently.
- Discuss who and when it is appropriate to hug others, including family members, friends, and acquaintances.

Building Language Development

Language increases your teenager's ability to interact with the environment and lead a fulfilling life. Addressing your teen's language and communication skills at home is an important step toward independence and successfully interacting with others.

During the teenage years, many individuals with Down syndrome are working towards understanding more abstract language, such as humor, words with multiple meanings and problem solving such as "What will happen next?" when discussing an activity or story. Teenagers continue to work on generalization and maintenance of skills across different social settings. This can be difficult for some teenagers with Down syndrome, so feedback from family members and friends is very important for their language and communication development to continue to mature.

Tips and activities to build language development:

- Provide regular feedback on communication. Slowly model what your teenager should be saying. Repetition, practice and support will help in increasing their communication skills.
- Talk about appropriateness in conversations. Talk to your child about feelings and empathy, by asking questions, such as "How do you think that made him feel?" or "When you walk away while he is talking to you, he thinks you do not want to talk to him". Listening with your whole body is a good strategy to teach. This feedback is critical in improving both language and social skills.
- Provide a slightly higher level of language within your home than what the teenager is currently using. This will, in time, promote higher level language skills.
- Practice conversation maintenance by taking turns. Ask a question about an ongoing or recent activity and wait for a response. Visual supports such as pictures or photos of an activity can be used to support this type of communication. Continue to increase the number of times you and your child stay in the conversation. Maintaining the topic is an important social language skill. If your teenager goes off topic and begins to talk about something unrelated to the conversation, bring the teen back to the conversation for a few more interactions. Remember that daily practice, praise and patience are needed to develop these skills.
- Recognize your child's signs of non-verbal communication through his or her body language and facial expressions. Attach words to nonverbal communication, as this communicates that their message has been heard. Simple words are best like, "that was fun!" in response to your child's facial

expression or gesture. Continue to work toward building a larger gestural vocabulary. Many teenagers with Down syndrome have difficulty reading non-verbal communication correctly. Be patient with this, as progress may be slow.

- Photo communication books about activities that are important to the teenager are useful tools to encourage interaction with friends and family. Most individuals with Down syndrome have a stronger learning modality when information is presented to them visually, then bring in the often weaker auditory learning modality. Use this support to increase receptive, expressive and social language development.
- Every communication experience for a teenager with Down syndrome is a learning opportunity. Take the time to listen and respond appropriately. These are small steps to the bigger goal of improved communication development.

Building Gross Motor Skills

In the teen years, your child continues to become more and more independent. He or she will be more involved in choosing their own activities based on their interests. Continuing to engage in physical activity or exercise is important during this time, particularly with the many changes that are happening to their body during adolescence. Some teens are naturally drawn toward physically active hobbies, such as dance or sports, and that is great! Continue to foster their skill development and participation. If your child is more interested in less active hobbies, such as movies, music, or video games, try to find a balance between active and relaxing time. No matter how your child gets involved in physical activity, it is necessary for all children and adults with low muscle tone to stay active in order to gain and maintain muscle strength. As the old saying goes, “Use it, or Lose it!”

Look at motor skills in everyday activities: There are movement components in almost all everyday activities. Feeling confident, strong, and competent in movement skills will help your teen get the most out of an activity. For example, when your teen goes to the school dance, she may feel unsteady walking in her fancy dress shoes rather than her comfortable gym shoes. The feeling of hesitancy may prevent her from experiencing all the fun of dancing and socializing with friends.

Some activities to consider:

- Daily personal care activities: Dressing and personal care activities require good balance and coordination, in particular balancing on one foot for dressing and bathing. If your child has difficulty stepping over the tub, putting their foot in a pant leg, or feels they may slip in the shower, they may feel nervous or resist

performing these daily activities. While working on any strength or balance challenges to improve these skills, also consider making modifications to the environment (a non-slip mat in the tub) to help your teen be safe and successful.

- **General mobility:** Your teen likely moves around in your home easily and comfortably. Continue to work on balance and strength so that your child feels comfortable walking and moving around in a variety of environments and on stairs, ramps, etc. This will ensure that your child is able to navigate his or her school environment successfully. Imagine all that goes in to getting textbooks from a locker, navigating a crowded hallway or stairwell, and finding the correct classroom!
- **Unique or new situations:** Your teen may need some advanced preparation for a new activity or situation. Think about the motor components involved in the new activity and talk about them or practice them with your teen. For example, if he or she is going to an amusement park for the first time, discuss waiting in line for the rides, and simulate stepping down or over a threshold to sit down in the seat for the ride. Knowing what to expect and feeling confident in how to handle this new situation can go a long way toward a positive experience!

General health & fitness: An active lifestyle should be encouraged to maintain strength and balance and for overall health. There are both physical and emotional benefits of physical activity and exercise including cardiovascular fitness, maintaining a healthy body weight, and emotional well-being. A healthy body leads to a healthy mind!

Tips and activities to encourage health & fitness:

- For overall health, the Center for Disease Control recommends children and teenagers recommend 60 minutes of physical activity most-to-all days of the week. Check with a doctor before beginning an exercise program. This may sound like a lot, but your teen may already be getting some of this through daily activities like gym class or walking between classes. Initially, your teen may not be able to complete 60 minutes of exercise. That's OK! Begin to work toward that goal. If they can complete 10 minutes, begin at that level. Every week, aim to increase the exercise time by 3-5 minutes. You can also break up exercise bouts. For example, take a 10 minute walk after breakfast, lunch, and dinner.
- Find active leisure activities that are enjoyable for each individual. Dancing, swimming, walking, bike riding, dance/exercise DVDs or video games, etc. Some people enjoy exercising at home, while others like getting outside or to a gym.
- Participate in active leisure activities with friends and family: a nature walk at the

local forest preserve, playing basketball in the driveway, line dancing, swimming at the community pool or beach. Everyone is more likely to participate in active leisure activities when they are having fun and spending time with important people in their life

- Discover what motivates each individual and use goals to see the progress: A step counter/fitness tracker, an app with colorful charts, a goal sheet with a reward, the time spent with a family member/friend when exercising together are all examples of motivators. Use what works best for your teen, but avoid food as a reward.
- Some teenagers with Down syndrome have difficulty with balance. Activities that can help improve balance include tai chi, yoga, and dancing.

Building Fine Motor Skills

During the teen years, fine motor skills need to be further developed. They will expand upon the skills learned in earlier years and use them more extensively in school, social activities, personal hobbies and interests and eventually, volunteering and work settings. Skills will become easier to perform and be executed with greater dexterity, especially if used on a regular basis. As with the younger years, practice is key.

Tips and activities to build fine motor skills at home:

- Practice sorting laundry. This can progress from separating clothing pieces (socks, pants, shirts, etc.) to learning how to fold each type of clothing, towels and other items. They can also learn to do the laundry from start to finish. Visual charts and instructions are important tools to use when learning this chore.
- Kitchen skills can further develop, too. Teach your teen how to cut their own food and slice foods for a dish you are preparing. Begin with easier foods, such as cucumbers, strawberries, bananas, etc. When they are comfortable with those items, introduce cutting up onions, carrots and meats. Have them serve a food to everyone, too. Include them in shopping for the ingredients of their food and don't forget to have them write the items on the grocery list or formulate a list using the computer. Following a recipe incorporates many fine motor skills, including stirring, measuring, scooping, etc. Get them involved as much as possible. As they gain confidence, give your child written instructions or picture sequences to learn how to use the microwave to heat up leftovers and other basic cooking tasks. Don't forget to include the cleanup tasks, too, such as wiping down counters, putting away ingredients, and washing (or at least drying) the dishes.

- Explore new ideas for hobbies or expand on ones they are already enjoying. A trip to a hobby store, bookstore or extra gym time can all be used as rewards for a job well done at school or home.
- Teens enjoy their personal space, now more than ever. Any written paper, school project or completed craft can be framed or highlighted and put on a display shelf in their room. This positive reinforcement often leads to continued efforts in these areas.
- Personal care, such as showers, hair care, shaving and menstrual care all require continued hand strength and coordination. Teach these skills in steps, using checklists and charts to help them learn without needing as many prompts from parents.
- Board games that require fine motor skills include Sorry, Yahtzee, Monopoly, Risk, Mancala, checkers and chess, to name a few. Card games, including dealing, use these skills and help to strengthen hands. Jigsaw puzzles are great for promoting fine motor and social skills, if done with a group.

Glossary

Co-contraction: the action of completely stiffening one part of the body by contracting muscles on both sides of a joint

Dexterity: accurate and efficient hand movements for function

Digital palmer grasp: a grasp used to hold a pencil or tool, in which the handle is stabilized in the palm, while the thumb, second and third fingers extend to the end; the second stage of grasp development

Expressive language: the ability to put thoughts into words and sentences in a way that makes sense and is grammatically accurate

Fine motor skills: the small movements of the body that use the small muscles of the fingers, toes, wrists, lips and tongue

Gross motor skills: the large movements of the body including rolling, sitting, crawling, standing, walking, running, and jumping

Hyperextension: “locking” a joint by over-extending it, using the skeletal stability rather than muscle control

Hypotonia: the condition in which muscles don't have the normal amount of tone, or contraction, so they appear loose or floppy

Ligamentous laxity: Ligaments are connective tissue that help support our joints. Ligamentous laxity, which is common in people with low muscle tone, results in increased mobility and possibly decreased stability around the joints

Muscle power: the ability to contract a muscle for a quick or explosive movement

Muscle strength: the ability to contract a muscle and generate force

Palmer grasp: a grasp in which the utensil or pencil is held firmly in the palm by all the fingers and thumb; the first stage of grasp development.

Pincer grasp: the thumb and first finger come together to pick up small objects

Physical activity: Any activity that gets your body moving and burns calories.

Pragmatic language: verbal and nonverbal skills that are used during social interaction with others

Pronation: When related to fine motor skills, it is the normal resting position of the forearms and hands (palms down). When related to gross motor skills, it is when the foot and/or ankle roll inwards, placing weight on the inside of the foot.

Prone: laying on one's stomach

Quadruped: positioned on one's hands and knees

Rating of perceived exertion: way of measuring physical activity intensity level. Perceived exertion is how hard you feel like your body is working. Even though each person rates their own work level, it is found to be a good estimate of heart rate during exercise.

Receptive language: what we understand and comprehend, such as following directions and understanding a story that was read

Sensory integration: the neurological process that organizes and integrates sensations from the body and the environment in order to make an adaptive response

Speech: the verbal ability to make the sounds that become words, the physical act of talking. Speech consists of articulation (how speech sounds are made), voice (the use of the vocal folds and breathing to support speech) and fluency (the rhythm of speech)

Supination: When related to fine motor skills, it is the rotating of the wrist to turn the forearm and the palm up. When related to gross motor skills, it is the rolling outward of the foot and ankle.

Supine: laying on one's back

Visual motor: refers to activities in which the eyes guide hand movements

Wide base of support: positioning the body part, typically the arms or legs, spread wide apart.

Resource List

Suggested Books:

Boyfriends and Girlfriends: A Guide to Dating for People with Disabilities by Terri Couwenhoven

Down Syndrome Parenting 101: Must-Have Advice for Making Your Life Easier by Natalie Hale

Mental Wellness in Teenagers with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges by Dennis McGuire & Brian Chicoine

Social Skills Picture Book for High School and Beyond by Jed Baker

Teaching Children with Down Syndrome about Their Bodies, Boundaries and Sexuality-A Guide for Parents and Professionals by Terri Couwenhoven

The Guide to Good Health for Teens & Teenagers with Down Syndrome by Brian Chicoine & Dennis McGuire

The New Social Story Book, Revised and Expanded 10th Anniversary Edition: Over 150 Social Stories that Teach Everyday Social Skills to Children with Autism or Asperger's Syndrome and their Peers by Carol Gray

Who's the Slow Learner? A Chronicle of Inclusion and Exclusion by Sandra Assiomotos McElwee

Suggested Websites:

American Heart Association: <http://www.heart.org/HEARTORG/>

Offers a variety of tools to live a healthy lifestyle, including nutrition and physical fitness activities.

Do2Learn: www.do2learn.com

Offers a variety of free social skill activities and tools.

Exercise for People with Disabilities: <https://www.youtube.com/user/sarahsgreatday>

YouTube channel of teen with Down Syndrome who does cooking and exercise demonstrations

Friendship Circle: <http://www.friendshipcircle.org/blog/>
Blog for parents of children with special needs.

Mitch Adaptive Fitness: www.mitchfitness.net
Certified inclusive fitness trainer. Contact information is provided for either in-person or phone consultations.

Muve: www.muve.com
Creative movement program that has follow-along videos, games, and a special needs section

Parenting Science: <http://www.parentingscience.com/>
Parenting tips and tools driven by science and research. Great tips on social skills.

Play Therapy Supply: <https://www.playtherapysupply.com/games>
This website has an array of games and activities to teach

Quizlet: <http://www.quizlet.com>
This website is a tool used to practice curriculum taught in the school setting

Woodbine House:
<http://www.woodbinehouse.com/Down-Syndrome.29.0.0.2.htm>
A continued list of books and resources about Down syndrome.

Suggested Phone Apps:

GoalTracker App: Available on Android and Apple phones

Tracking tool for personal fitness, health, budget, career goals and more.

HabitBull App: Available on Android phones

Tracking tool for habits and routines.

Pedometer App- Available on Android and Apple phones

Tracks the number of steps and aligns them to calories burned, distance, time walked and more.

Workout Trainer App: Available on Android and Apple phones

Variety of exercises, full workouts and physical fitness tips.

Suggested DVDs:

Shaun T's Fit Kids Club DVD Workout by Beachbody

Everyday Fitness with Jeff Rogers- A workout DVD that includes an adult with Down Syndrome

Gift List for Teenagers

- Scrabble & Scrabble, Jr.
- Apples to Apples
- Yahtzee
- Jenga
- Jigsaw puzzles
- Address books
- Cookbooks
- Good quality shoes for taking walks and hiking
- Gift certificates for bowling, community plays and other outings
- Wii game systems, especially games that promote movement and turn taking.
- Pedometer or fitness tracker
- Dance, Yoga or Workout DVDs
- Sports Equipment- soccer ball, tennis racquet, basketball and hoop, rollerblades, ice skates,
- Foosball or ping pong table
- Bike
- MP3 or music speakers
- Karaoke machine
- Photo albums for teens to put photos of their activities, family events, etc.
- iTunes gift cards

About the Authors

GiGi's Playhouse thanks our amazing team of therapeutic experts!

Lyndsey Menning is a physical therapist working in the Northwest Suburbs of Chicago. She completed her undergraduate degree in kinesiology and exercise physiology at the University of Wisconsin and her Masters degree in physical therapy at the University of North Carolina at Chapel Hill. She has spent the last 13 years working in Early Intervention and private practice. She specializes in treating the birth to age eight population, serving children with a wide range of developmental delays and disabilities, including many children with Down syndrome. She enjoys bringing her clinical expertise into the home setting to make it accessible and practical for families in the early years of their child's development.

Chris Newlon has served on the Board of Managers for GiGi's Playhouse McHenry County for the past 6 years in a variety of roles. She is also a public speaker and outreach specialist for the National Association for Down Syndrome, with a focus in schools and hospitals. Chris worked in Adolescent Psychiatry and with people with Eating Disorders as a licensed OT in Ohio and Illinois. She is the mother of five children, ages 12 to 28, the youngest of whom has Down syndrome.

Lora White is a pediatric speech and language pathologist in private practice in the northwest suburbs of Illinois. She has spent the last 35 years working with children with developmental disabilities and their families. Lora has extensive training in oral motor/ feeding issues and the communication development of children. Her practice consists of many children with Down syndrome.

Kenzi Huelskoetter has her Type 03 Teaching License and has spent all of her career in educational and recreational program management.

Daniell Bargstadt is the National Programs Manager at GiGi's Playhouse. She conducts research and development to grow our programs, enhances program materials, and provides training, support and guidance to program staff and volunteers. Daniell has been with GiGi's for over 12 years, as a founder, a board President, a local program coordinator, and now a member of the national staff. On the personal side, she's the mother of 5 children, the youngest of which is Olivia, a teenager with Down syndrome shown at left. You can reach Daniell at dbargstadt@gigisplayhouse.org, or by submitting a Zen Desk ticket in the category of Programs. Daniell is honored to have worked so closely with our team of experts to complete this project!

Bibliography

A special thanks to the authors below who shared their research and books with the world. We've used their learnings to help us create this book for GiGi's Playhouse.

American Heart Association

Brian Chicoine & Dennis McGuire

Centers for Disease Control

Gregory V. Payne & Larry D. Isaacs

Maryanne Bruni

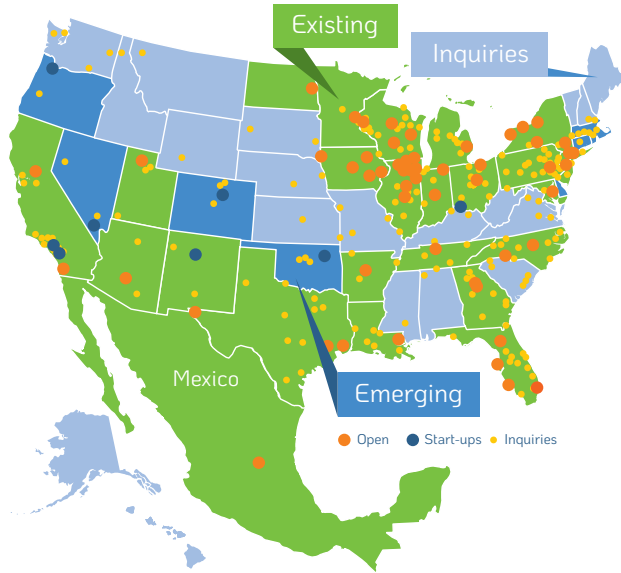
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Patricia C. Winders

Sandra Assimotos McElwee

Terri Couwenhoven

Disclaimer: Please note that the activities and exercises within this book should not replace therapeutic intervention. It is best to consult your therapist or speech and language pathologist who is trained to individualize to the needs of your child. Their guidance will be important for successful development.



Down Syndrome Achievement Centers
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Locations across North America, including Mexico, and still growing!

Check our website for a location near you!

gigisplayhouse.org

