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The Road Map of HollandTown

HollandTown



FAMILY



HOME LIFE



HEALTHCARE



FINANCES



DISABILITY GROUPS



FRIENDS



FIRE STATION



POLICE



SAFETY



SCHOOL

EDUCATION

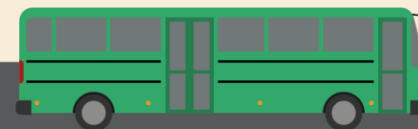


RECREATION



CAFE

COMMUNITY ACCESS



TRANSPORTATION



SPIRITUALITY



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***Remember the
digital classroom at
www.arcjc.org/login***



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Family



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Disability & the Family: Common Concerns

- The relationship between parents is often more stressed
- Many parents have trouble getting their extended family on board with the reality of a disability diagnosis
- Parents struggle to find time to meet their child's medical and therapeutic needs
- Feeling like you have to do all the work and coordination on your own.
- Worrying about how the typical siblings will be affected



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Who can help me?

- Parent support groups
- Sibling support groups
- Marriage and family counselors
- Pastoral care
- **You**



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***Let's take a quick look
at resources in the
online classroom.***



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Home Life



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Disability at Home: Common Concerns

- Physical adaptations and modifications to your home
- Promoting safety in the home
- Purchasing medical supplies
- Dealing with behavioral issues
- Addressing communication needs
- Helping others understand your child
- Respite and general child care



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Who can help me?

- Parent networks (in-person and online)
- Health-Related Specialists
 - Physical Therapists
 - Occupational Therapists
 - Speech Therapists
 - Behavioral Therapists
 - Primary provider/pediatrician
- CCB Resource Coordinators
- Google



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Healthcare



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Healthcare: Common Concerns

- Managing your child's healthcare needs
- Paying for your child's healthcare needs
 - Is Medicaid an option?
 - What are waivers?
- Understanding your insurance coverage
- What to do when you've been denied a service
- Finding therapists and providers
- Feeling overwhelmed for not knowing enough



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Who can help me?

- Doctors & Specialists
- Physical Therapists
- Occupational Therapists
- Speech Therapists
- Behavioral Therapists
- Insurance Company Customer Service
- Children's Hospital Family Navigators



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Finances & Legal



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Financial & Legal: Common Concerns

- Paying for your child's unique needs
- Planning for your child's needs if something happens to you
- Special needs planning
- Applying for SSI/SSDI
- What's the ABLE Act?



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Who can help me?

- Estate Lawyer – *Creates legal plans*
- Financial Advisor – *Advises on how to fund plans*
- Parent networks (in-person and online)
- Internet
- Government program administrators



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Education



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Education: Common Concerns

- *Too many to list!*
- Understanding your student's rights
- What's all the fuss about inclusion?
- Knowing how the process works
- What to do when the process breaks down
- The school's role in delivering therapeutic services



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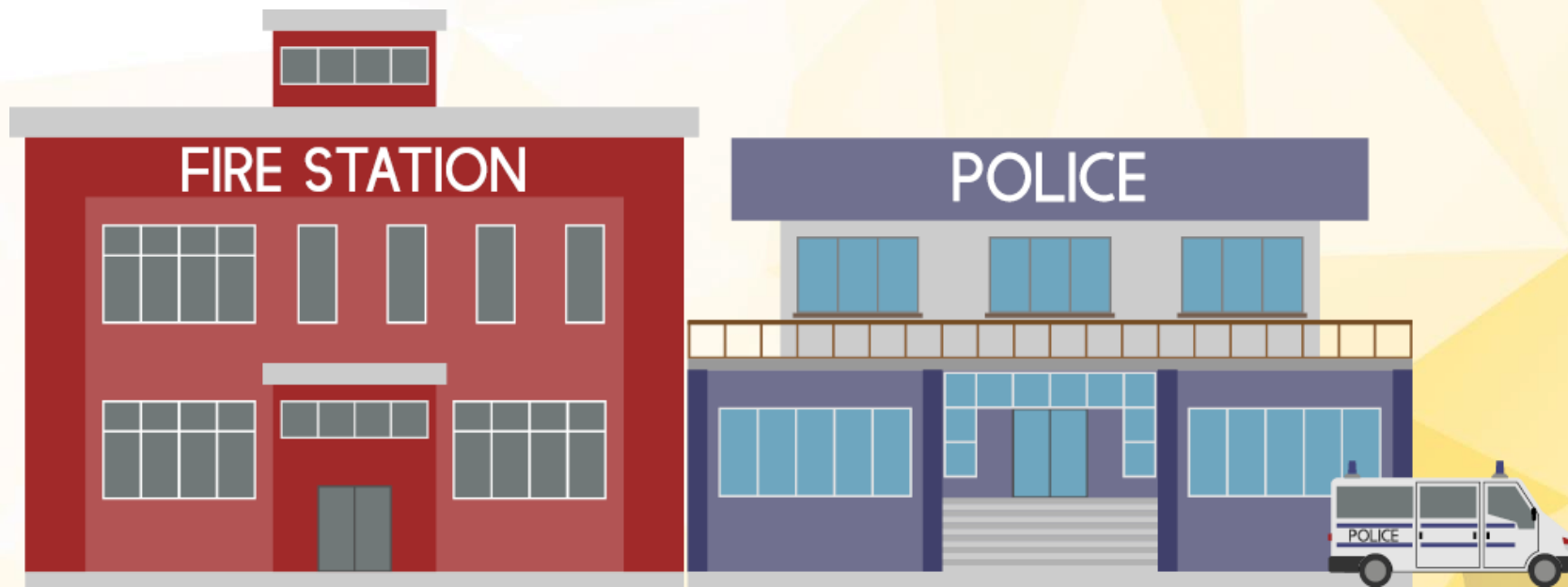
Who can help me?

- Advocates
 - The Arc's advocates
 - Paid special education advocates
 - Special education lawyers
- Parent training organizations mandated by law (ex. PEAK Parent Center)
- Parent networks (in-person and online)
- Your child's school team
- **You**



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Safety



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Safety: Common Concerns

- Maintaining my child's safety in different environments
- My kid is a runner
- What if my child gets lost
- My child injures themselves or others



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Who can help me?

- Community safety (Police & Fire)
- Behavior therapist
- Your medical team
- Parent networks (in-person and online)
- You



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Friendships



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Friendship: Common Concerns

- Helping your child find friends
- Strategically building friendships
- Building friendships through recreation
- Building a parent network for yourself
- How do typical kids make friends?



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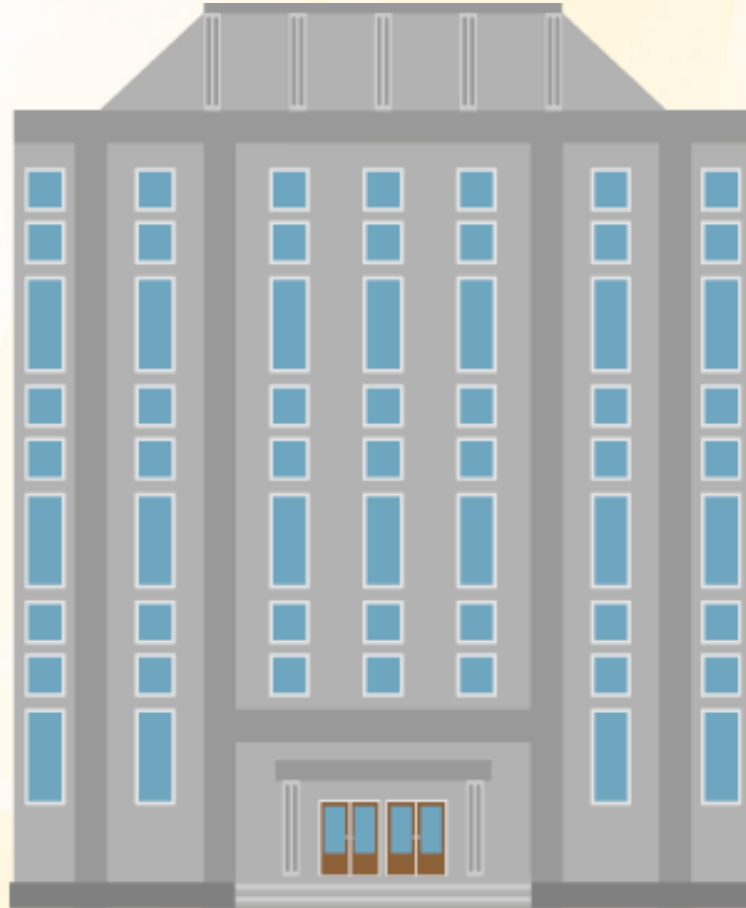
Who can help me?

- Coaches and activity leaders
- Parent networks (in-person and online)
- Support groups
- Sibling Clubs
- You



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Disability Groups



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Disability Groups: Common Concerns

- Sorting out who does what
- Understanding Community Centered Boards (CCBs)
- Categorizing disability groups
- Sorting out the acronyms
- What does The Arc do?



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Categorizing disability groups

- Government entities:
 - Ex. Social Security, Medicaid, Health & Human Services
 - Can be federal, state or local level
- Quasi-Governmental entities
 - Ex. Community Centered Boards
 - Services funded by a blend of public and private dollars
- Community-based non-profit organizations:
 - Ex. The Arc, Sibling Tree, RMDSA, Autism Speaks
 - Largely privately funded with a specific scope of work



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Understanding CCB Authority & Funding

- Community Centered Boards are quasi-governmental organizations in the state of Colorado, whose current role is to coordinate and deliver government services for people with I/DD
- CCBs, per state statute, determine disability using a stricter definition than the federal government.
- Services funded by Medicaid dollars administered by the Colorado Department of Health Care Policy and Finance
- Additional funding comes from local mil levy dollars



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Colorado Definitions of Developmental Delay and Disability

Visit DDRC online and click “Show Definition” to see more.

<http://ccb.ddrcco.com/developmental-disability-resources/developmental-disabilities-services.php>



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What Services do CCBs Provide?

- Case Management
- Service Coordination
- Waiver Administration
- Service Provision
 - Cash subsidy (Family Support)
 - Behavior Team
 - Depending on waiver, can include:
 - Respite care
 - Therapies
 - Home healthcare
 - Other services for adults



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Who can help me?

- The Arc
- Resource Coordinators
- Community groups
- Parent networks (in-person and online)
- Google



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Favorite Resources: Disability Groups

- *The list is too long!* Please visit the online classroom to learn more.



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Recreation



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Recreation: Common Concerns

- Inclusive recreation experiences
- Therapeutic recreation services
- Summer and day camps
- Supporting your child in typical recreation environments
- Paying for recreation



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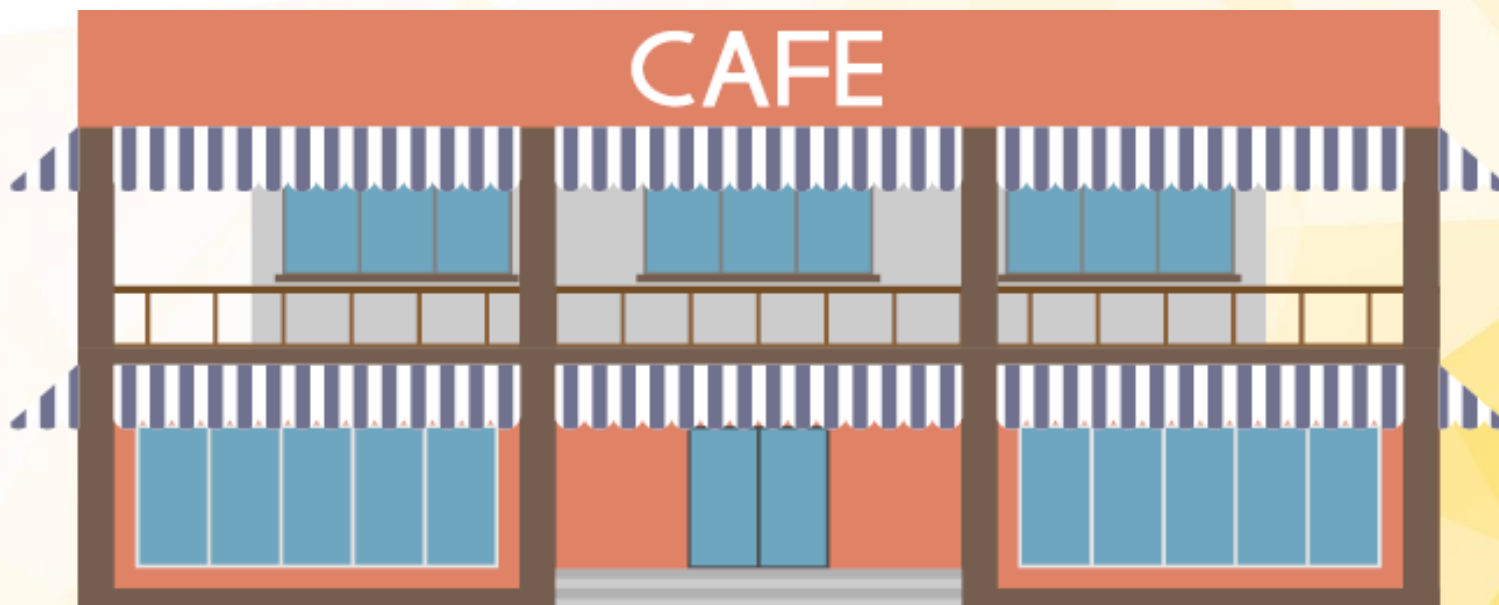
Who can help me?

- You and the coach or leader in charge
- Parent networks (in-person and online)



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Community Access



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Community Access: Common Concerns

- The places you want to go aren't physically accessible
- Food issues – special diets, difficulty eating, alternative feeding methods
- Going to the bathroom – will there be an accessible bathroom? Will you be able to change diapers or catheters?
- It feels like people are staring at or judging you
- You're not sure how to explain to strangers, or if you should
- Fear of being asked insensitive questions, or of how you'll respond
- Overcoming obstacles to community



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Sharing with Strangers

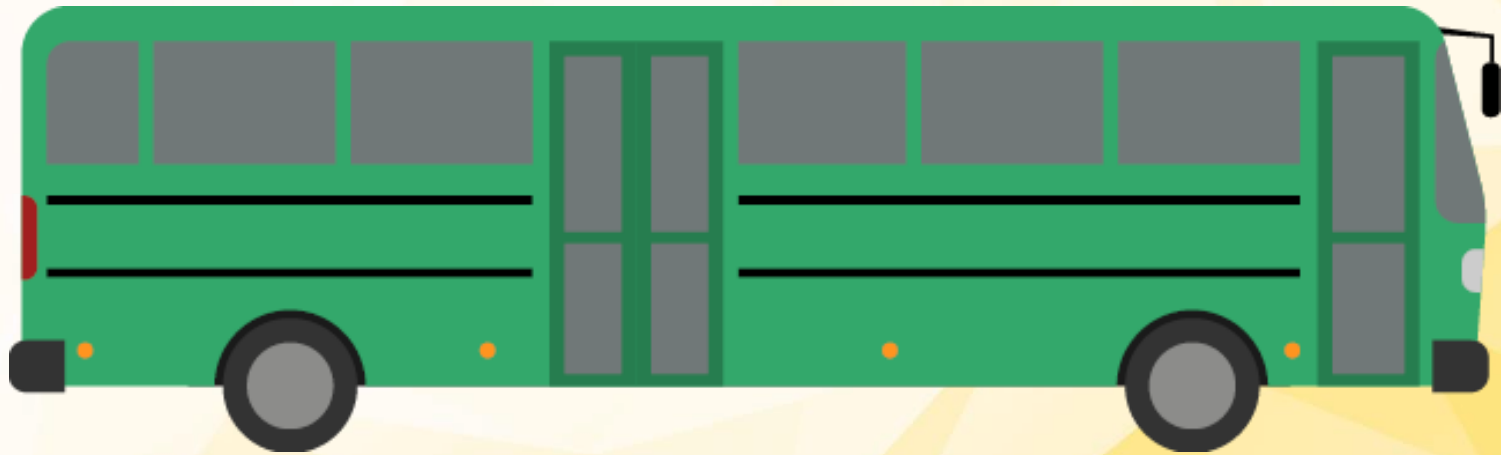
- The brief statement: *“He has autism”*
- A slightly longer story introducing your child and any things strangers need to be aware of: *“he doesn’t talk, he doesn’t like hugs, he loves trains”*
- The whole shebang, for when you meet someone who is familiar with situations like yours and it all spills out.

Homework: Take time to draft your 2-3 minute stranger introduction. You will be sharing this with the group the last night of training.



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Transportation



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Transportation: Common Concerns

- Accessible vehicles
- Parking placards
- Air travel concerns
- Are you the only one that can lift a wheelchair?



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Who can help me?

- The internet
- Parent networks (in-person and online)
- You



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Spirituality



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Spirituality: Common Concerns

- Childcare for my child during service
- Disruptive behaviors or vocalizations
- Finding welcoming churches
- Knowing when to move on



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Who can help me?

- You
- Faith community leadership



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Tips for finding a spiritual community

- Google: “Special needs [church/synagogue/ministry] Denver”
- Talk to your community’s leaders
- Talk to other parents
- Be willing to help other’s learn



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Your Roadside Advocacy Kit



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Critical Skills & Tools

- Communicating effectively
- Conflict Resolution
- Assertiveness
- Researching
- Organizing
- Resourcefulness
- Resiliency



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Closing

- Table Talk
 - What are your top concerns today?
 - Where do you need to get started?
 - Who can help you ?
 - What can wait until later?



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Homework:

- Work on your 2-3 minute family introduction
- Check out online classroom!