

Supporting Parents with IDD: A Canadian Perspective (Through An Ontario Lens)

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Outline

- Parenting Enhancement Program (PEP) at Surrey Place
- Early Years of the Program (1980 -1994)
- The Impact of Societal Change
- Evolution of PEP and the Therapist Role
- Current Program Description
- Building a Community of Support
- Case Study
- Trillium Grant
- Future Directions



FACES OF PEP



Lisa Malcho, *PEP Therapist*



Linda Wise, *PEP Therapist*

Clockwise:

Jayne Carnwell, *Service Coordinator-Intake*; Dawn Brown, *Manager*; Deborah Bluestein, *PEP Therapist*; Alicia Gonen, *PEP Therapist*; Jeanny Scantlebury, *Senior Director of Adult Services*; Nya Daley, *PEP Therapist*

Who are we?

- **PEP Staff come from various backgrounds**
 - Child Development
 - Applied Behaviour Analysis
 - Social Worker
 - Early Childhood Education
 - Rehabilitation Services
 - Psychology

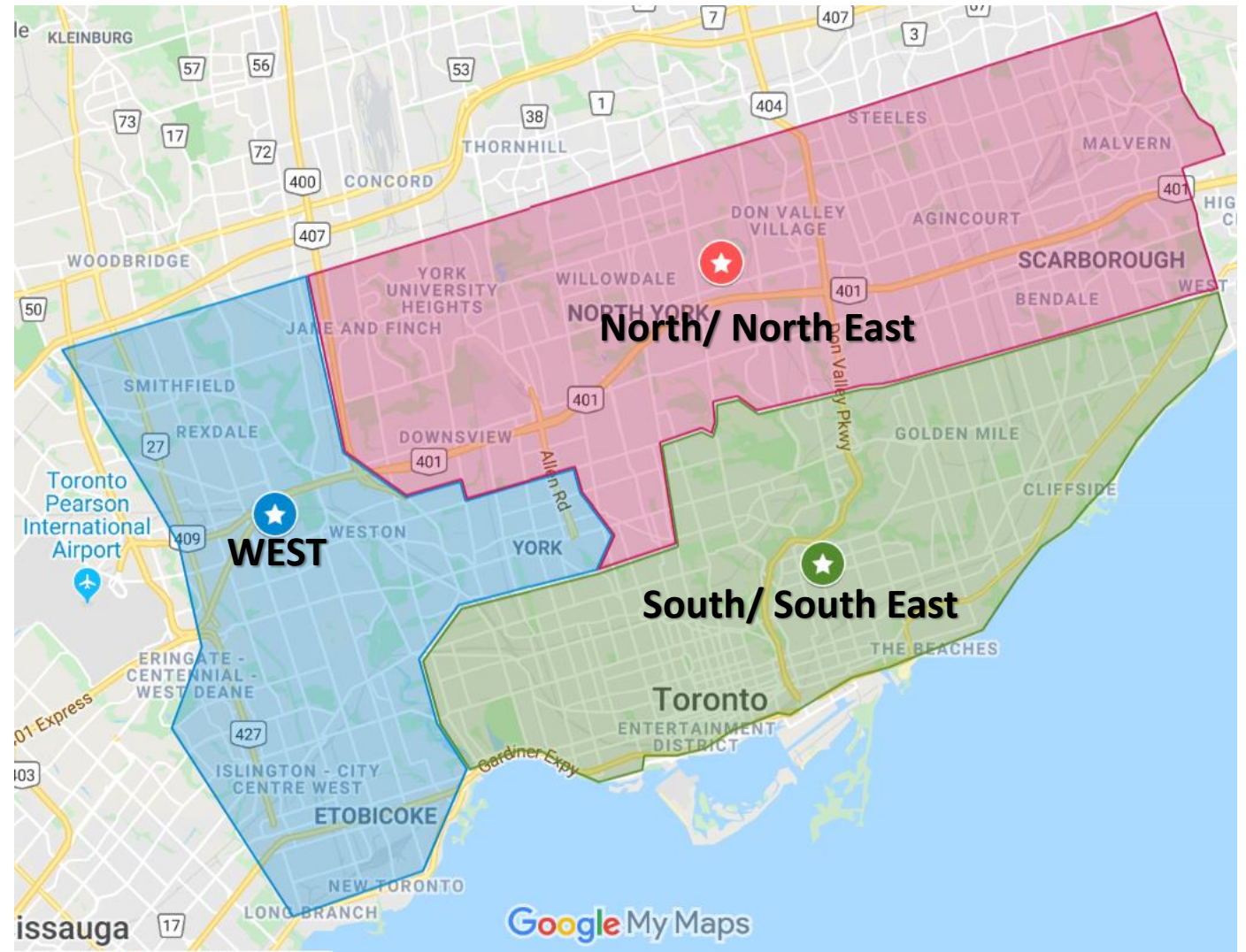
Where are we?



Where are we?



Where are we?



What do we mean by IDD?

- Traditionally, we have used the term *developmental disability* (DD) in Ontario
- Recently, there has increased use of the term *intellectual or developmental disability* (IDD)
- Eventually, this will be replaced by *intellectual developmental disorder*, as defined in the DSM-5

Early Years of the Parenting Program (1980 – 1994)

Parenting Support: The Late 70s

- No services tailored to parents with IDD at Surrey Place
- Therapists in the Infant Stimulation program at Surrey Place noticed that the mothers of some of the babies who displayed delayed language development appeared to have difficulty interacting with their baby

Parent Education Project

- In 1980, Surrey Place got a 2-year grant for a *parent education* project
- Two full-time therapists
 - One therapist had a background in early childhood education
 - One had BA in psychology and experience in early childhood education
- One half-time research coordinator
 - Support data collection and recruitment (intake and screening)

Parent Education Project

- Early on, the director responsible for the project observed that project staff were so busy dealing with the parents' day-to-day challenges, it was hard to focus on an education intervention
- Maurice Feldman was asked to lead the project

Parent Education Project

- The initial focus was on increasing parents' stimulating interactions (e.g., imitating, praising) and physical affection with their child in order to improve child language outcomes
- Basic behavioral strategies were used, targeting one behavior at a time
- Results were good in the clinical setting, but the mothers did not seem to generalize these skills to their home environment

Parent Education Project

- In 1982, Surrey Place got a 5-year grant to continue the *parent education project*
- The model integrated research and service
 - Demonstrated the impact of parent training interventions
 - If a client's needs clashed with those of the research, the priority was always the client

Parent Education Project

- The Centre-based 'parent-child interaction' intervention shifted to a home-based intervention
- Once in the home, therapists saw that the mothers needed support and training in many basic childcare and safety skills
- Task Analysis checklists were developed for the various skills and the same behavioral strategies were used to teach the mothers

Parent Education Project

- Conducted a number of intervention studies looking at the impact of parent-child interactions on early language development
- A series of publications, starting in 1985, demonstrated the efficacy of this approach
- Dr. Feldman advocated for the project to become a funded program and it became the *parent education program* in the late 80s

Parent Education Program (PEP)

- *Step-by-Step Child-Care: A Manual for Parents and Child-Care Providers* was developed and implemented at Surrey Place by Dr. Feldman and staff of the Parent Education project
- The manual was published in 1993 and revised in 1998

PEP

- In 1994, Maurice Feldman left Surrey Place and PEP continued, under the direction of Dr. Nitza Perlman
- The scope of the skill-building work was expanded to include:
 - Attachment, interaction, and how to read your child's cues
- The program now had three full-time therapists and a full-time research coordinator

Parenting *Enhancement* Program (PEP)

- In the early 2000s, the program was renamed the Parenting Enhancement Program (PEP)
- In 2003, Dr. Perlman left and PEP also lost its research coordinator
- Since 2003, PEP has been staffed by three full-time therapists without any additional administrative support

The Impact of Societal Change (1970s – early 2000s)

The Impact of Societal Change

- By the mid 1970s, Ontario operated 16 institutions which housed more than 8,000 people with developmental disabilities
- In 1974, the Ontario government passed the Developmental Services Act
 - abandoned the medical model
 - focused on provision of community services, and signaling:
 - the start of de-institutionalization
- The goal was to have closed the last of the facilities by 2012

The Impact of Societal Change

- In 1990, Ontario passed the Child and Family Services Act
- In 1997, Ontario passed Making Services Work for People



Focus on family unification

- In 2006, the United Nations Convention on the Rights of Persons with Disabilities
 - Canada ratified the Convention in 2010 and the Optional Protocol in 2018

The Impact of Societal Change

- In 2008, Ontario passed the Social Inclusion Act
 - To provide the right supports so people with IDD can live more independently in the community
- In 2009, the last of 16 government institutions had closed
- In late 2012, the Office of the Ombudsman of Ontario launched an investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with IDD

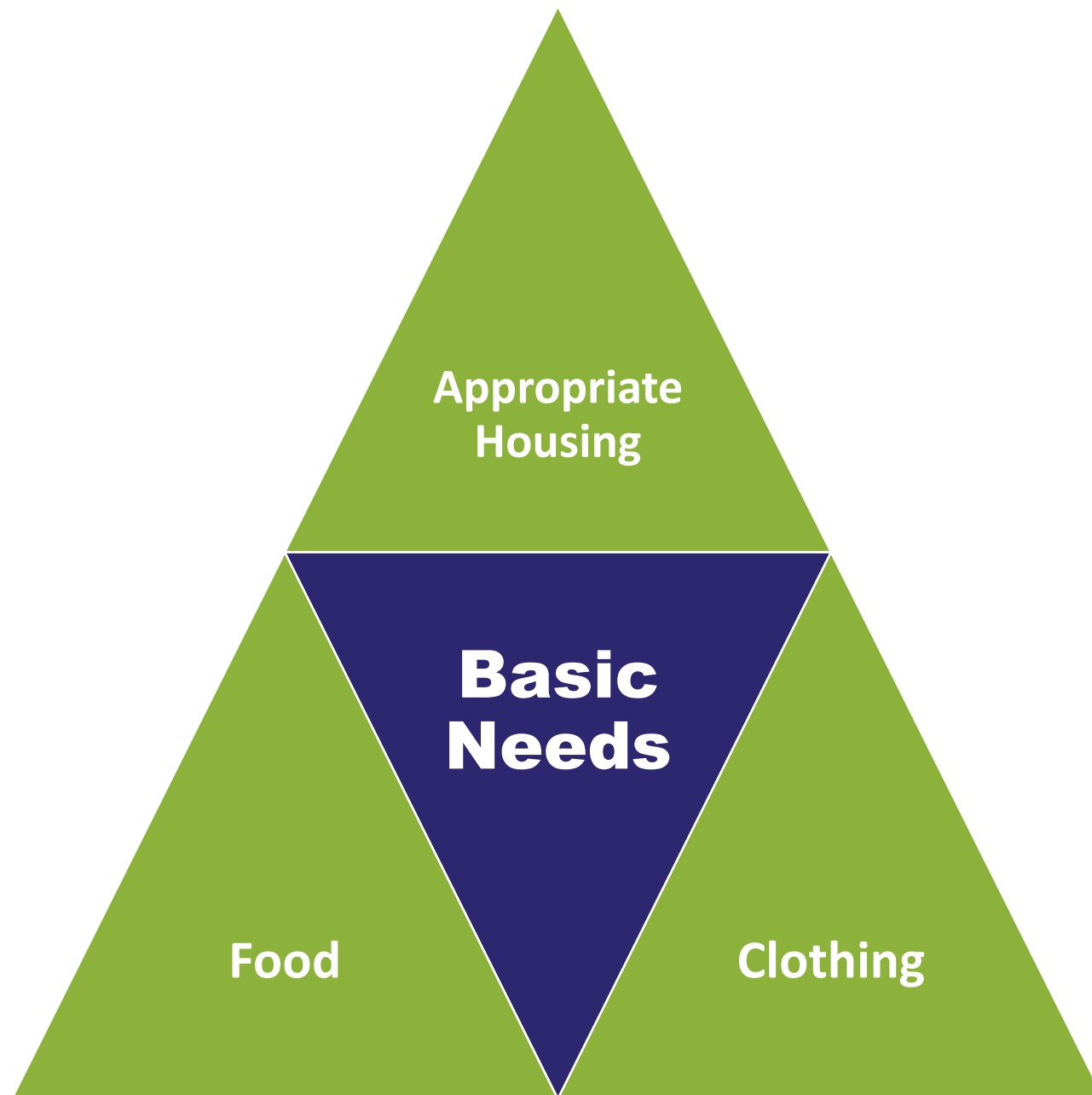
Evolution of PEP and the Therapist Role (2003 – 2019)

Evolution of PEP

- Over the years, the scope of the PEP therapists' role has expanded to identify and address some of the more complex, system-level, needs of these parents.
- The immediate need for other types of support can postpone the work on skill building.
- Often parent skill building is derailed by: financial, legal, property repair, relationship, disruption of daily routine, inclement weather, health (mental/physical), technology and social media.

Evolution of PEP

- Families appear to have to become more complex – more children identified with special needs and the systems to support them have become more difficult to navigate.
- The need to focus on developing individualized treatment plans – no two clients are the same.
- Increasing importance of case management:
 - Community integration
 - Coordinating and managing medical, education, psychosocial, and financial domains
 - The need to address ‘basic needs’



Evolution of Step-by-Step

Task Analysis

Temper Tantrums

PEP Checklist																
CONDITION: Baseline____Training____Manual____Maintenance____																
Parent_____								Date (mo/dy/yr)_____								
Child_____								Location_____								
Observer_____								Time from_____to_____								
Parent								Staff								
TANTRUMS age 1 to 2 years								NP	VP	I	M	PP	N/A	Sr+		
1) Parent recognizes probable reason(s) for tantrum:																
e.g., frustrated/needs attention/hungry/tired/overwhelmed																
2) Parent considers what has helped in the past																
3) Parent stays calm																
4) Parent reacts appropriately:																
e.g., comforts/backs off/ helps out/ verbalizes child's feelings/ takes to quiet place																
5) Afterwards, reassures child: e.g., hugs, praises for calming																
6) Reflects on appropriate ways to avoid in the future:																
e.g., positive attention/avoid overload/meals and snacks/sleep/avoid source of frustration																
Reference:																
NP=no prompt VP=verbal prompt I=instructions M=modelled PP=physical prompt N/A=not applicable Sr+=reinforced																

Current Program Description

Overview of Service

- Today, PEP continues to be a home visiting program that provides training and support to parents with IDD
- We strive to reduce the risk of child neglect and abuse and promote the social, emotional, cognitive and physical development of children
- Parents receive 1 to 2 hours per week for a 3-year service block

Admission Criteria

Voluntary Program

- ✓ Parents have demonstrated/confirmed eligibility through application to Developmental Services Ontario
- ✓ Children are between the ages of 0 to 8 years
 - ✓ Parent is the primary caregiver
 - ✓ Lives in the City of Toronto
 - ✓ Child considered at risk for neglect/abuse (most referrals from the child welfare agencies)



Assessment Process

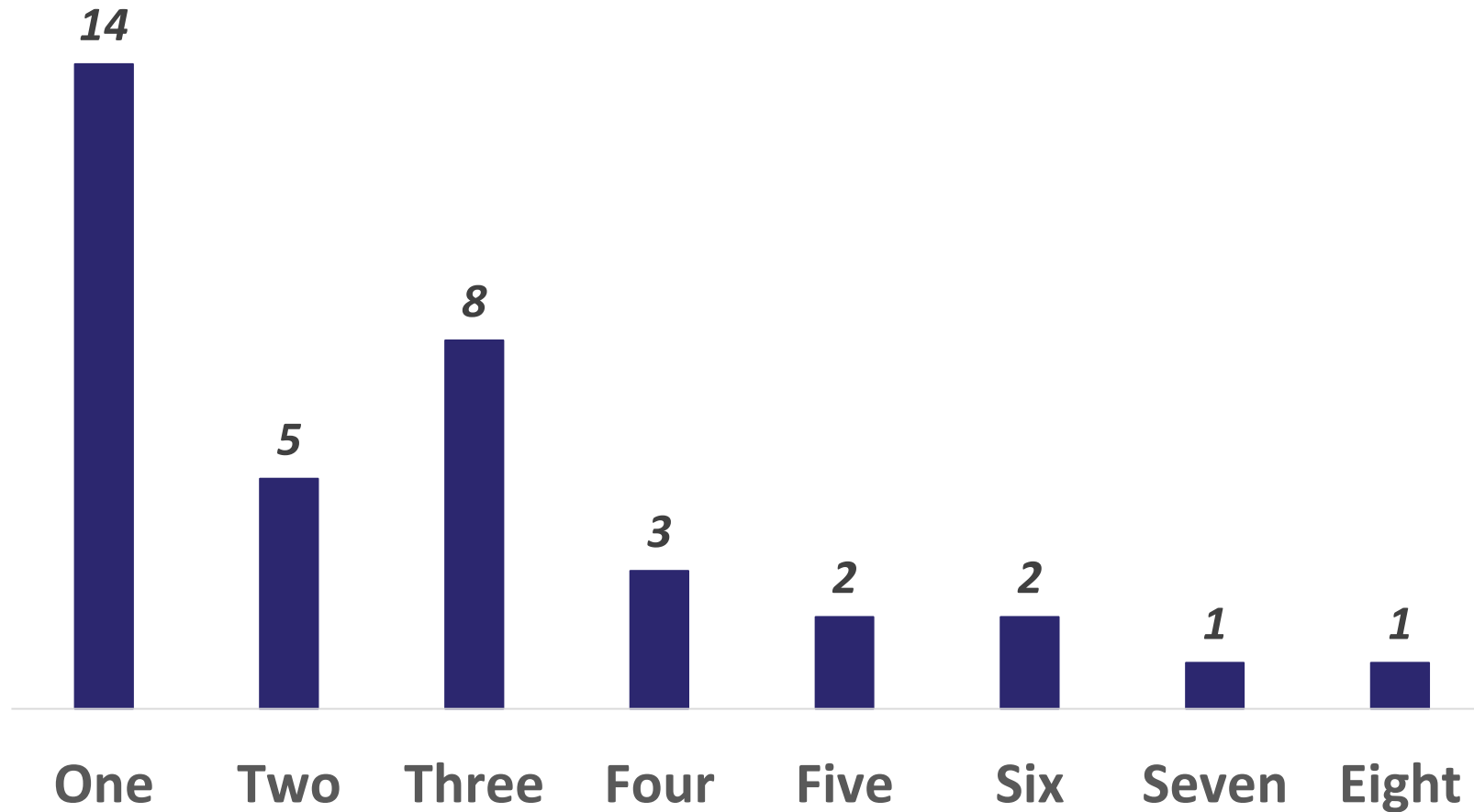
- Specific PEP Intake Assessment
- Identifying existing parenting skills (strengths and needs)
- Identifying and addressing risk factors
- Determining collaboratively what supports would be most beneficial
- Emphasis on building a trusting and supportive therapeutic relationship

Current Case Load

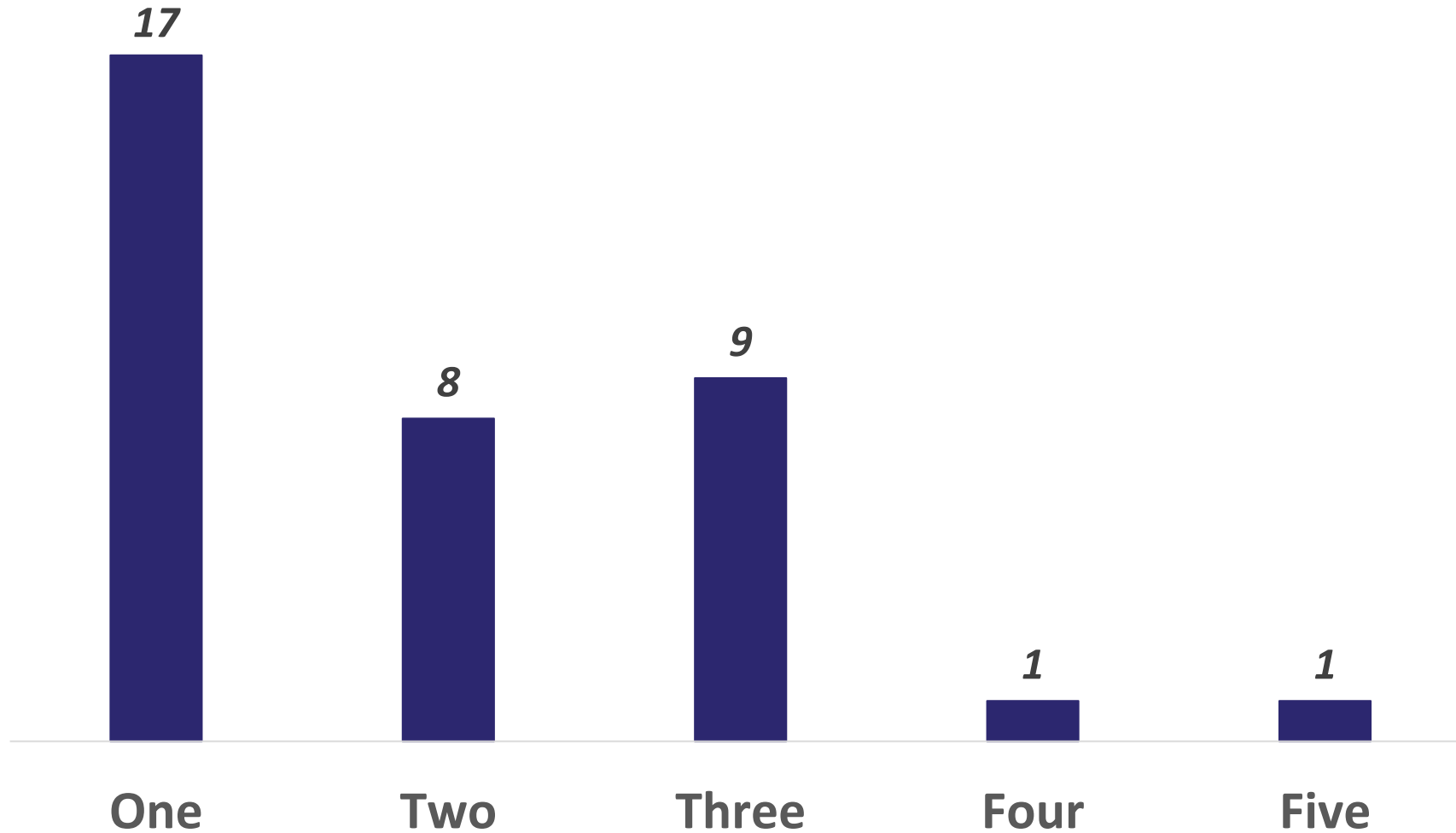
- Forty parents in service* :
 - 35 mothers
 - 5 fathers
 - 4 couples (i.e., both parents clients of PEP)
 - 36 families
- Seventy-one children in the custody of parents:
 - 27 with diagnosed special needs (38%)
 - 22 with suspected special needs (31%)

* There are 23 parents on the PEP waitlist

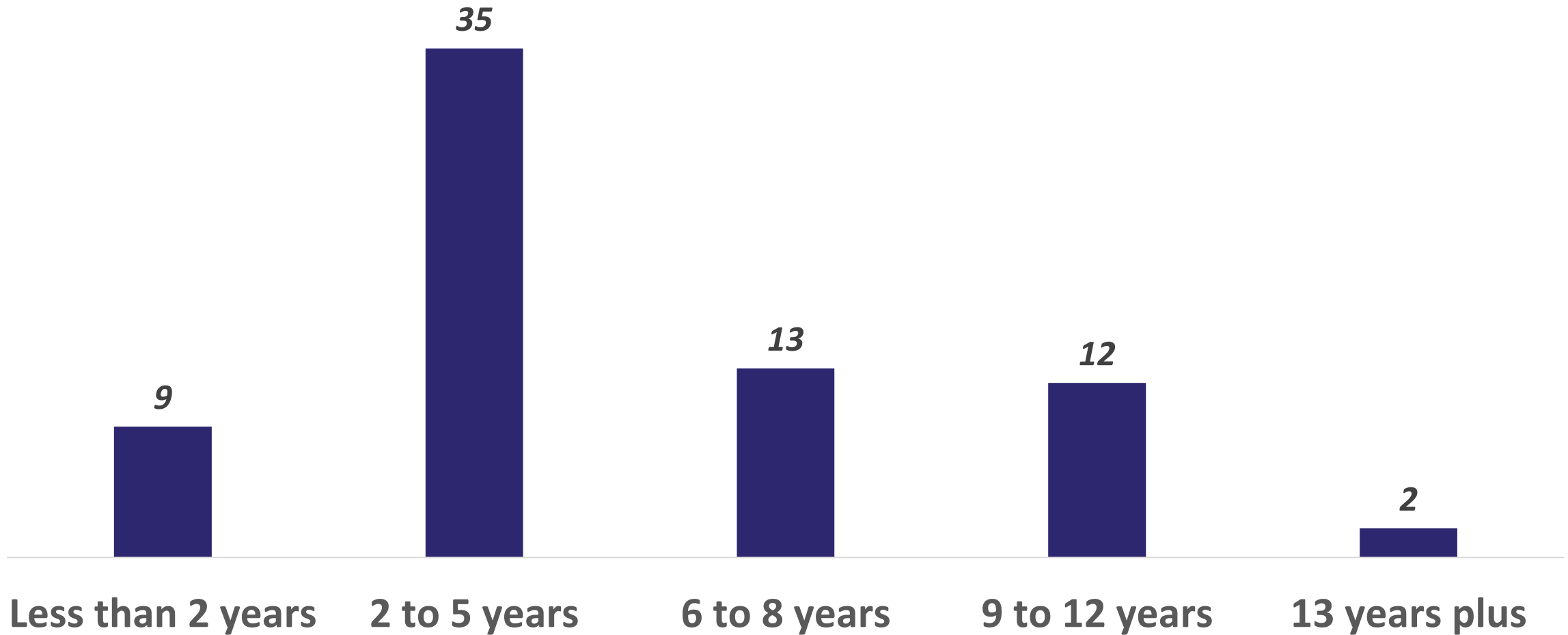
Number of Offspring per parent



Number of Children per Household



Ages of children in parental custody



Training & Support

- Strengthen secure attachment/parental sensitivity
- Monitor development of children and make referrals if necessary (e.g., Ages & Stages)
- Assist with skills of daily living
- Help organize (e.g., develop contact lists, calendars, binders, use technology)
- Support the development of self-sufficiency

Training & Support

- Provision of specialized performance-based training on a wide variety of skills (e.g., formula prep or how to manage temper tantrums)
- Parent skills training based on the Step-by-Step Parenting Model
- Training is focussed on skill development
- Adapting materials (e.g., Toronto Public Health material, communicate aids)

DEBORAH'S CHOICES



Remind

About making **GOOD CHOICES** and trying not to make poor choices today

GOOD CHOICES



Keeping my hands to myself

Being Honest

Telling the truth

Being nice to others

Poor Choices



Hitting

Not telling the truth

Talking back

Giving attitude



Review



I made **GOOD CHOICES** today- that earns me a bonus!
Bonus Ideas: _____



I made poor choices today - TOMORROW I will try harder for it to be a better day!

Visual Aid

Undesired Behaviour

Groups

- Groups are used to address the issue of social isolation that our families experience. The following are some of the groups that we have run:



Building a Community of Support

Building a Community of Support

- We advocate for parents and help them access services to build a community of support for themselves and their child(ren)
- Parents need help accessing multiple sectors:
 - Government programs (e.g., municipal, provincial, federal)
 - Specialized child development services
 - Healthcare
 - Education
 - Developmental Services

Financial Supports/Funding Options

- Ontario Disability Support Program (ODSP)
- Ontario Works(OW)
- Passport Program
- Disability Tax Credit, Assistance for Children with Severe Disabilities (ACSD), Special Services at Home (SSAH), Ontario Autism Program, Childhood Budget
- Easter Seals, Presidents Choice, Jennifer Ashleigh Children's Charity

Funding Landscape: ODSP

- Needs based; depends on living situation (including size of family):
 - Basic needs maximum: **\$815** (food, clothing & necessary personal items)
 - Shelter allowance maximum: **\$918** (mortgage, rent, utilities, property taxes, home insurance and condo fees)
- Average market rent for a one-bedroom apartment in Toronto: **\$1,270**
- ODSP includes health benefits
 - prescription drugs, vision, special diet, assistive/mobility devices, hearing aids and dental care
- Employment incentives and benefits
 - child care costs and items needed for work

ODSP Funding Example



- Family of 2
- Mom and 1 child (under 18 years)
- ODSP monthly breakdown:
 - Basic Needs \$815
 - Shelter \$500
 - ***Total ODSP monthly payment*** ***\$1315***

Specialized child development services

- Developmental Assessments
 - (e.g., CITYKIDS)
- Autism Spectrum Disorder
 - (e.g., Ontario Autism Program)
- Audiology
 - (e.g., Infant Hearing Program (IHP))
- Speech & Language
 - (e.g., Early Abilities, HRRH – Women and Children's Clinic, HSC, TDSB, TCDSB, etc.)
- Occupational Therapist and Physical Therapist
 - (e.g., VHA, Holland Bloorview Kids Rehabilitation Hospital)

Community programs



Health Services

- Mental Health and Counselling Services
 - CAMH, HRRH, Gerstein Centre and Saint Elizabeth (Etobicoke & North York), HSC Centre for Community Mental Health
- Dental
 - HSC, Holland Bloorview, University of Toronto
- Community Health Centres
 - Black Creek Community Health Centre, Local Health Integration Networks (LHIN), Unison Hubs
- Reproductive Health
 - Bay Centre for Birth Control (at Women's College Hospital)
- Toronto Public Health

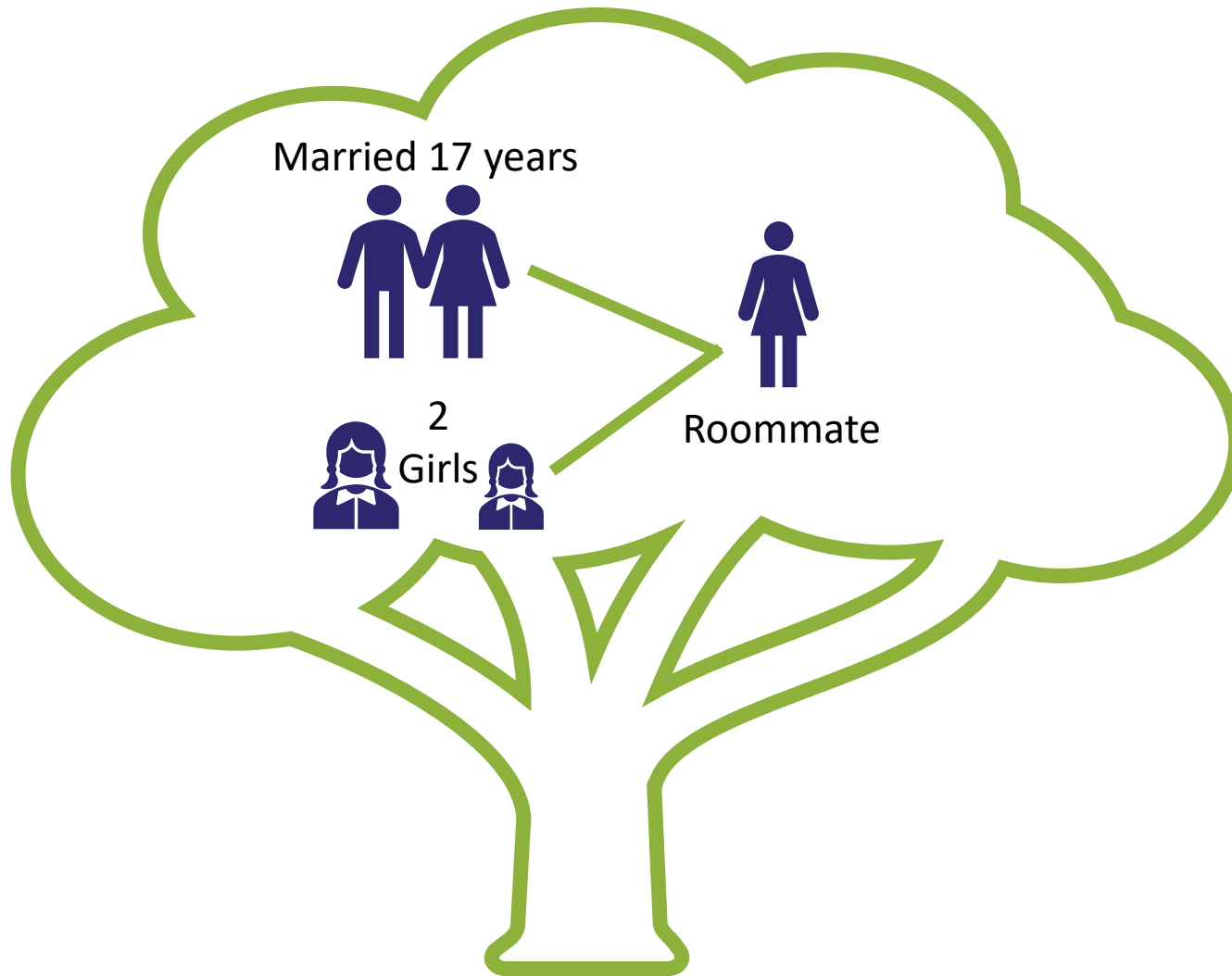
Other Community Partners

- Child Protection Agencies
 - CAS, CCAS, JF&CS, Native Child and Family Services
- School
 - IPRC meetings, tutoring for children, educational placement
- Employment Supports
 - ODSP , Employment Ontario, Pathways, March of Dimes, JVS, Project Work
- Parent education/Literacy
- TDSB, Public Libraries, YMCA, LINC

Case Study

The Harper Family

History & Demographics



- Both grew up in Toronto
- Went to the same high school and placed in Special Education classes.
- Been together for over 22 years
- Both have an IDD
- Daughters are 7 years apart in age
- Mr. Harper works part-time seasonal as a Kitchen Prep Worker
- Mrs. Harper stopped working once their second daughter was born
- They live with a female roommate that the girls refer to as Auntie

Reason for Referral to PEP

Original Referral

- Surrey Place Internal Referral – Psychologist, Child and Youth Department
- Identified as having difficulty managing parental stress and establishing routines for the children
(i.e., How to respond to tantrums in public spaces)
- Child welfare – actively involved

Current Needs

- Support in dealing with parenting stress
- Providing the children with consistency
- Discipline strategies

Positive Indicators

Heather

Functional level of literacy

Responds to direction

Takes control of her reproductive health

Support from roommate

Ryan

Functional level of literacy

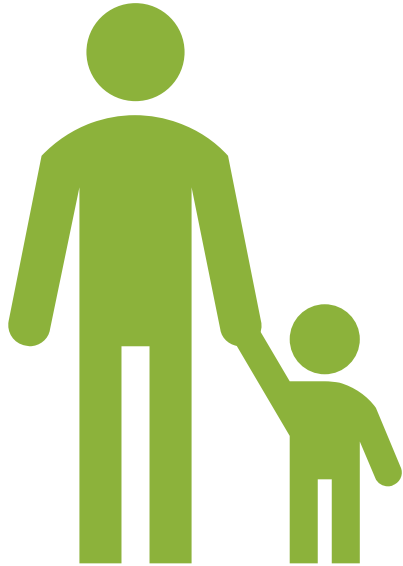
Willingness to accept help

Motivated

Supportive professional involvement

Support from parents

Risk Factors



Ryan

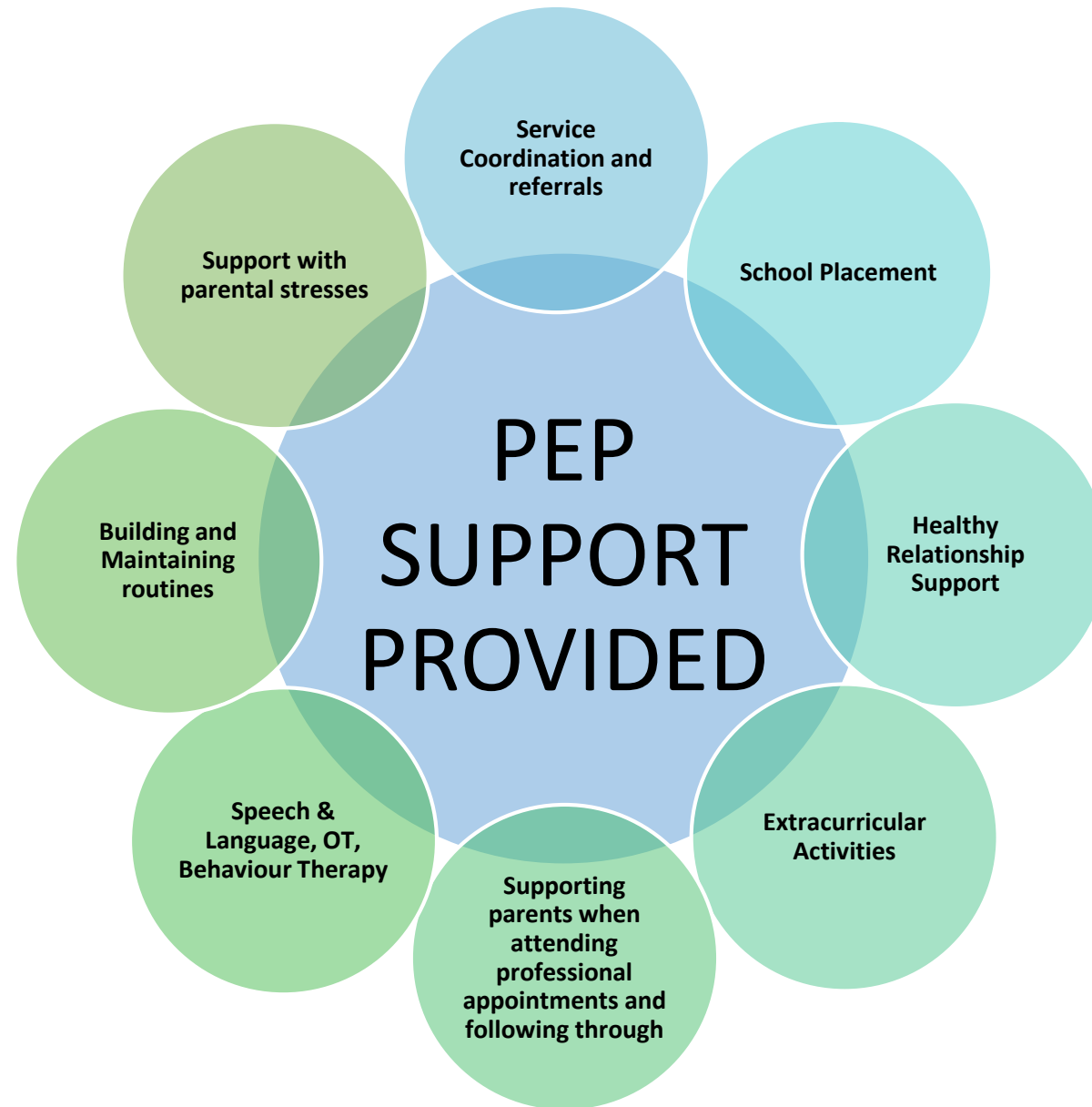
- History of domestic violence
- Mental health and temper tantrums
- Inability to cope with parenting stress and anxiety
- Lack of peer interaction

Risk Factors



Heather

- Unresolved issues of trauma
- Inability to cope with parenting stress and anxiety
- Heavily influenced by the roommate
- Lack of flexibility
- Lack of external parenting supports



Ontario Trillium Foundation

Grow Grant



OTF Grant: Year One Objectives

- Hire one full-time PEP therapist*
- Increase service access to 10 parents with IDD
- 10 parents demonstrate increased parental sensitivity and parenting skills
- Reduce the risk of child neglect in 10 families
- Needs assessment of community stakeholders

OTF Grant: Year Two Objectives

- Increase service access to 20* parents with IDD
- 20* parents demonstrate increased parental sensitivity and parenting skills
- Reduce the risk of child neglect in 20* families
- Outcomes/satisfaction monitoring: clients and outreach to community stakeholders
- Analysis of outputs and waitlists
- Develop relevant education/outreach activities

OTF Grant: Year One Activities

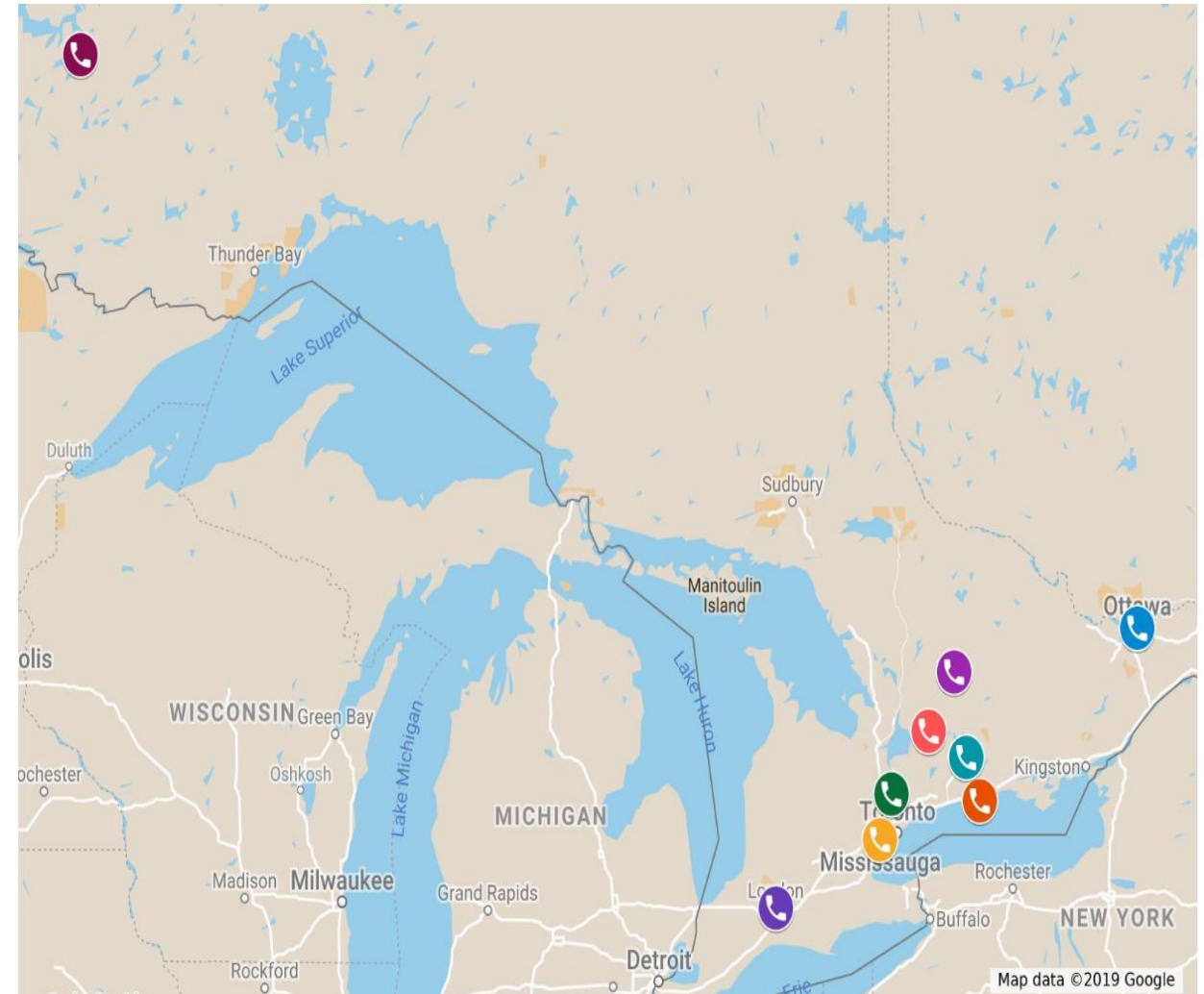
- Team brainstorming re: community stakeholders
 - Identify priority stakeholders
- Currently running focus groups with parents
 - Involving medical students in the grant work with parents
 - Where do the parents see challenges?
- Interviews with key community stakeholders
 - How often do they interact with our clients?
 - What do they need?

Gaps and Grant Activities to Date

- Extensive waitlist and only three (permanent) PEP Therapists to serve four quadrants in the city of Toronto
 - Hired two full-time PEP therapists
 - Shadowed the permanent therapists (cases transferred)
 - Started opening cases from the waitlist in June, 2019
- There is minimal perinatal support for mothers with IDD
 - Currently partnering with a perinatal support worker program to develop curriculum
- Parents need long-term intermittent support (i.e., beyond the 3-year service block)
 - Developing new groups for returning parents
 - Exploring the 'consult' model for returning parents

Gaps and Grant Activities to Date

- PEP is the only in-home parenting support program available in Ontario for parents with IDD and is limited to the city of Toronto
- Currently responding to a request for training in the community





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What field/sector do you work in?

- Developmental disability sector
- Child welfare/protection
- Child development
- Education/Training
- Legal
- Government
- Parent
- Other

**In what capacity are you involved
with parents with IDD?**

What are the most significant challenges you face in supporting parents with IDD?