

## Background, Sample and Method

### Background

People with disabilities historically have experienced extreme forms of discrimination or oppression related to parenting:

- Forced sterilization of the eugenics movement (O'Brien, 2011).
- High rates and of CPS involvement and termination of parental rights (LaLiberte, Piescher, Mickelson & Lee, 2017; McConnell, Aunos, Feldman, & Prasad, 2011; Slayter & Jensen, 2019), despite research showing that IDD does not necessarily correlate with the likelihood for abuse or neglect (Emerson & Brigham, 2014; McGaw, Scully & Pritchard, 2010)

There currently are few formal supports to assist parents with disabilities with their parenting, as the support and service system for adults with disabilities focuses on supporting people with disabilities as individuals, rather than as parents or caregivers (Lightfoot & LaLiberte, 2011).

### Sample

Criteria: Adults with intellectual, developmental and/or physical disabilities, and at least one child 18 or younger

Disabilities: Count	1-4 diagnoses per parent, mean = 2.33
Disabilities: Diagnoses	Autism Spectrum Disorder, Mild Cognitive Impairment, Fetal Alcohol Spectrum Disorder, Scoliosis, Fibromyalgia, Chronic Pain, Traumatic Brain Injury, Spinal Chord Injury, Mobility/Partial Paralysis, Multiple Sclerosis. (55.6% acquired)
Additional Mental Health Diagnoses:	Major Depressive Disorder: 66.7% Generalized Anxiety Disorder: 11.1%
Family Composition	Single parent: 55.6% Coupled with other parent: 44.4%
Age of Parents	Range 27-55 years, mean = 40.67
Race/Ethnicity of Parents	Caucasian (55.6%), African American (44.4%), Native American (11.1%)
Number and Ages of Children	1-5 children per household 0 – 5: 23.5% 6 – 12: 47.1% 13 – 18: 29.4%

### Collection and Analysis Methods

- Data collection/sources: Intake paperwork, interviews with participants and key support people, case notes from goal-setting meetings
- Quantitative Data: Demographic and Descriptive, prevalence and means
- Qualitative Data: Thematic analysis of participant interviews, goal-setting charts, and notes from meetings

## Study Purpose and Intervention Process

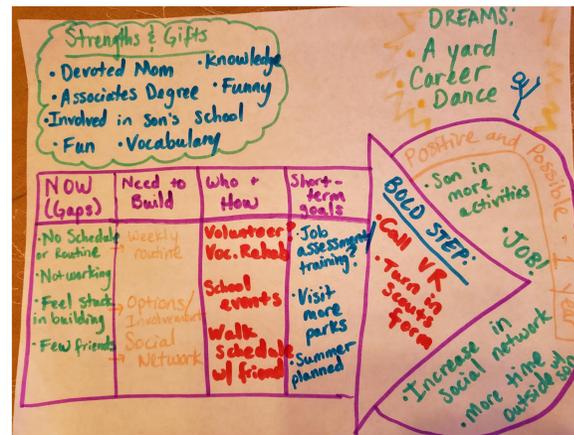
### Purpose

**The purpose of this study is to explore the strengths, needs, goals and levels of support for parents who have disabilities.**

This qualitative study is part of an intervention study, aimed at testing the effectiveness and feasibility of parent-centered planning, a supportive goal-planning intervention, modeled after person-centered practices (O'Brien, Pearpoint, & Kahn, 2010).

### Goal setting intervention:

1. Dreams for the future
2. Positive and Possible goals for one year
3. Identification of gaps and needs
4. Short – term goals (3-6 months)
5. Bold/Next steps



## Findings: Goals and Strengths

### Goals for Parenting

- Increase social networks
- Increase child involvement in activities
- Employment activities
- Stable/improved housing
- Connection to social services
- Parenting-specific (i.e. deal with challenging behavior of one child, talk to child about why his dad was not in his life)



### Parent and Family Strengths

- Use of and knowledge of the social service system
- Dedication to children
- Desire to learn and try new things

### References:

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 O'Brien, G. V. (2011). Eugenics, genetics, and the minority group model of disabilities: Implications for social work advocacy. *Social Work, 56*(4), 347-354.  
 O'Brien, J., Pearpoint, J. & Kahn, L. (2010.) *The PATH and MAPS Handbook: Person-centered ways to build community.* Toronto: Inclusion Press.

## Findings: Needs and Challenges

### Isolation and limited social opportunities

- Support limited to social connections within their building/living area
- Support staff (paid) are a main source of social interaction

### Informal support networks are fragile

- Participants experienced loss of friendships:
  - During participation in the study
  - As a (perceived) result of acquired disabilities



### Challenges with paid staff

- Paid staff are key support, so when they leave their job, the support is lost (and the friendship gone)
- Paid staff are there to help the parent with their individual needs, not the child's needs or parenting needs. Example: laundry

### Mental Illness is high among parents with Intellectual, Developmental and Physical Disabilities

- 66.7% reported a co-occurring mental health diagnosis
- Yet only half of those with mental health diagnosis (33.3% of sample) reported to be receiving mental health services (psychiatry, counseling, ARMHS)

## Implications and Next Steps

### Implications for Practitioners and Policy-Makers

- Like other adults with disabilities, parents with disabilities are often isolated and have limited social support networks. There is a need for increased social opportunities for families, that accommodate parents with disabilities and their children.
- Program rules regarding paid staff impede assistance with parenting-related activities and responsibilities.
- Mental health needs of parents with disabilities are often going unmet. Practitioners should be aware of high potential for mental health needs, and provide appropriate assessment and referral for services.

### Next Steps for Research

- Test effectiveness of the Parent-Centered Planning intervention in the areas of goal achievement and strengthening of social support networks.
- Explore use of Parent-Centered Planning in a variety of settings.