

**The information
seeking behaviours
of parents of
children with Autism
Spectrum Disorders**



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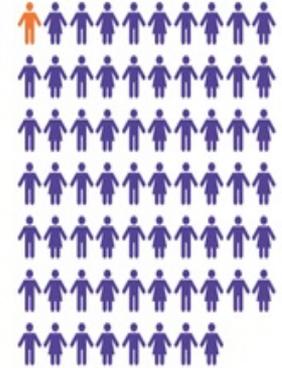
Overview of Presentation

- Statement of Problem/Justification
- Purpose of study/ Relevance to LIS professionals
- Research questions
- Definition of terms
- Literature Review
- Methodology
- Data analysis and results
- Findings and discussions
- Limitations of Study

Statement of Problem

- **78%** increase in prevalence of Autism Spectrum Disorders between 2002-2008 (CDC, 2010)
- Prevalence has gone up from **1 in 88** for the year 2008, to **1 in 68** for the year 2010 (CDC, 2014)
- Rate of autism in school age children has reached **1 in 94** in the area of Calgary (Ghali et al.,2014)

NUMBER OF CHILDREN IDENTIFIED WITH ASD



1 in 68



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

Purpose of study

To explore, with reference to parents of children with Autism Spectrum Disorders:

- Information needs
- Information seeking behaviours
- Information Sources
- Barriers to access to information
- Evaluation criteria used for information sources

Justification

- Increase in prevalence of ASD means parents will need more information to cope and care for children
- Study by NEDSAC (National Epidemiologic Database for the Study of Autism in Canada) indicates information need of parents most important of all needs. (Brown & Ouellete-Kuntz, 2010)
- Readiness of information professionals to provide information?
- Work on their role in guiding consumers and caregivers to web sites posting authoritative, unbiased, and current health information specific to an individual's needs (O'Neal et.al, 2012). (Services to marginalized/ Underrepresented populations)

Research Questions

- **Where** do parents **search for information** to take care of their children with Autism Spectrum Disorders?
- What are the specific **purposes** for which parents of children with Autism Spectrum Disorders are looking for information?
- What **criteria** do parents of children with Autism Spectrum Disorders use for **evaluating** their information sources?
- What are the **barriers** parents of children with Autism Spectrum Disorders face in finding the information they are looking for?
- Do parents of children with ASD feel that information agencies are meeting their **information needs**?

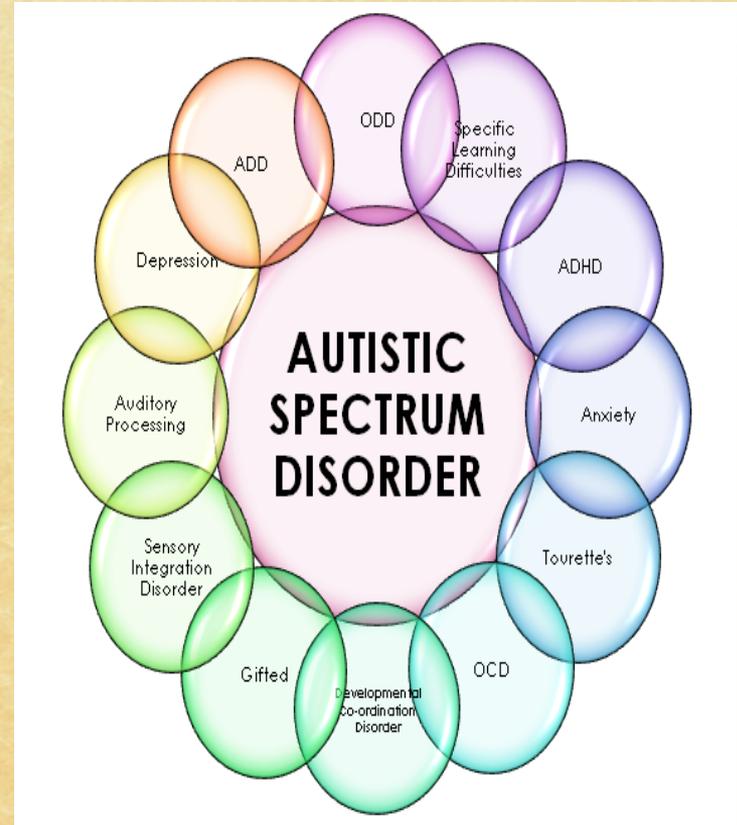
Definition of terms

Autism Spectrum Disorder: Lifelong developmental Disability characterized by:

- Deficits in social communication and interaction
- Restrictive & repetitive patterns of behaviour

Diagnosis is usually reached around the age of 2, some children do not get diagnosed until age of 4

Diagnoses of ASD include several conditions that used to be diagnosed separately earlier: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger Syndrome. (CDC)



Definitions: Information Seeking Behaviour

Marchionini provides a definition of this term as “a process in which humans **purposefully** engage in order to change their state of knowledge” and which is “closely related to learning and problem solving” (as cited in Case, 2002, p. 75)

Xie (2010, p. 2592) states “information seeking refers to the **purposive** behaviours involving users’ interactions with either manual or computer-based information systems in order to satisfy their **information goals**”.

Wilson(2000) defines information seeking behaviour as the **purposeful** seeking for information as a consequence of a need to satisfy a **goal** .

Literature Review

- Most studies in information seeking in the context of ASD are child centered with fewer studies focusing on the information needs of parents. (Lord et al., 2006)
- Focus on ethnicity, or a different disability (Alat, 2006; Lai & Ishiyama, 2004; Martinez, 2009; Oprescu et al., 2013)
- Health information seeking- stress, anxiety, depression (Walsh et al.,2012; Liesen, 2012)
- Readability level of materials (Sabo, 2008)

Literature Review

Fain (2009) and Zeng (2013) -specific diagnosis of ASD but focus on internet use only

Information seeking interpreted as a coping and problem solving strategy, (Pain, 1998)

Internet use hindered by low SES/eHealth literacy. (Knapp et al., 2011; Twombly et al., 2011)

Lack of monitoring of online materials (Martland & Rothbaum, 2006)

Methodology

- **Sampling:** Purposive, convenience Sample
- **Sample size and characteristics:**
- **Recruitment:** Not for profit organization(Flyers), personal connections(Word-of- Mouth)
- **Inclusion criteria-** Having at least one child under 18 diagnosed with ASD (Twins)
- **Methods:** Semi-structured interviews (30-60 mins)
- **Study type:** Qualitative

Data Analysis & Results

1. Where do parents search for and find information?

- Libraries
- Collegial Networks (School teachers)
- Professional networks (OT)
- Government agencies (FSCD)
- Not-for profit organizations (ASEA)
- Health care Centres, agencies and professionals(Glenrose)
- Parent networks
- Internet
- SNS
- Books & Print materials)
- Policy/procedure manuals,
- Information packages,
- Resource sheets
- Conferences
- Workshops
- Newly diagnosed parents meetings
- Google
- Web 2.0 (Facebook)

2. Purposes for which parents are looking for information

Medical/Health

Treatment Plans

Medication

Healthcare providers/Professionals

- Doctor/Pediatrician/Psychologist/OT
- Speech therapy-
- **Physical Activity**-for children with Impairments (Free2Bme at U of A)

Managing symptoms and behaviours

Diet and Nutrition- GFCF diet

Others

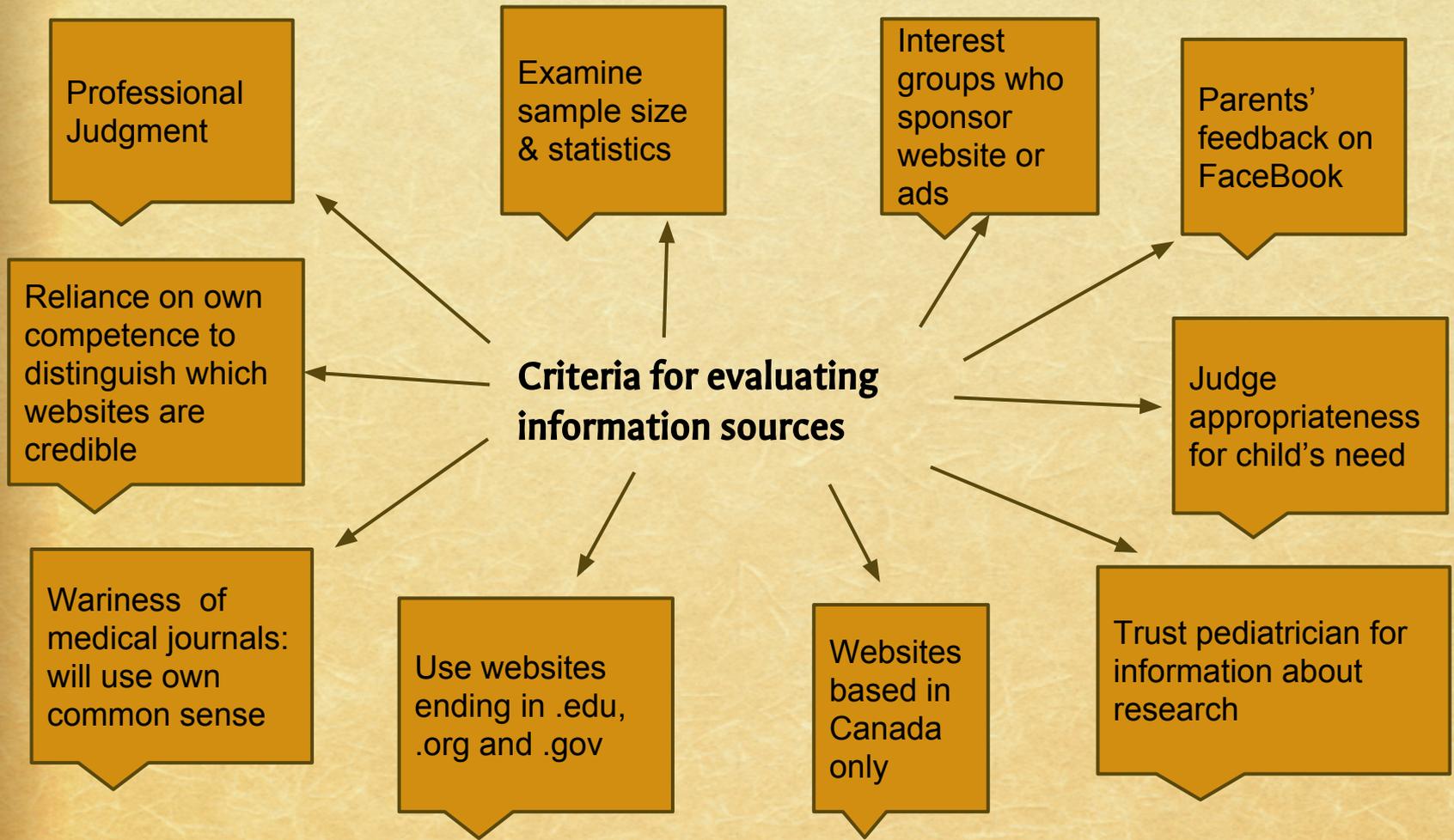
Respite-Hiring of caregiver

Education: IPP, Home schooling, Visuals, Transitions (elem- J/high), Strategies

Transportation

Sleep

Social services(FSCD)

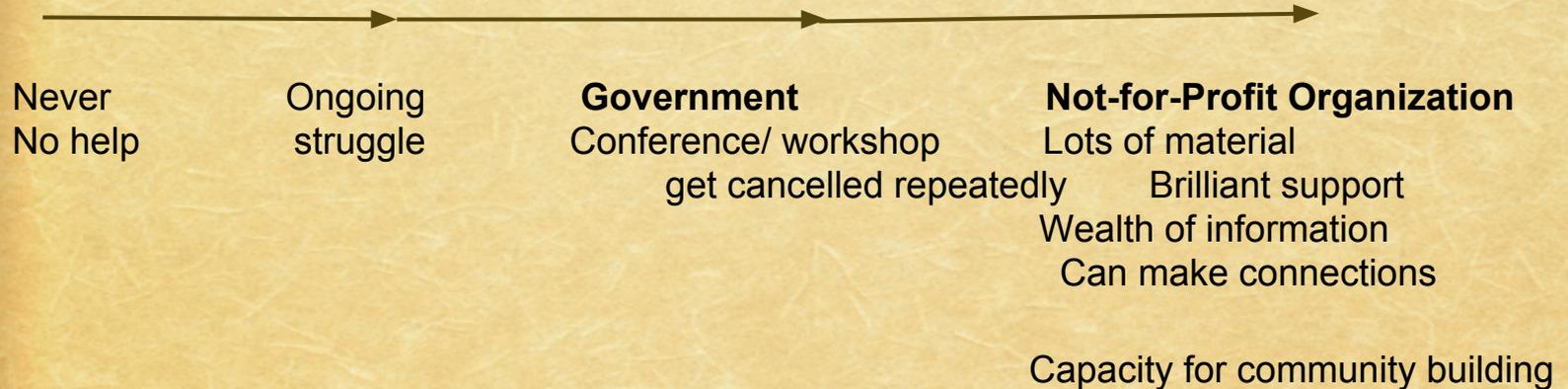


4. Barriers in finding Information

- “Too much @#\$%&!” on the internet nowadays-need to sift relevant from irrelevant
- Information scattered in different sites/places “do not have time to go places”
- Researchers doing their piece and publishing separately
- Commodification of information- “Not fair”
- Services more difficult to come by than information

5. Do information agencies meet your information needs?

Responses on a continuum from none to an abundance



Discussion of findings: Theory

- Notion of uncertainty and anomalous state of knowledge (ASK) (Belkin, et al., 1982)
- Everyday life information seeking - in specific situations but everyday transactions (Dervin et al. 2005; Savolainen, 1995)
- Concept of “serendipity” of information or information encountering (Erdelez, 1999)-related to finding information that can be useful (Transportation, Free2Bme)
- Wilson’s second model of information seeking “activating mechanisms” as motivator’s for information seeking: diagnosis of ASD is a trigger and information seeking is a coping strategy

Discussion: Previous research

Feeling overwhelmed and confused by excessive online information (Martos, 2013) and this also relates to information overload and information avoiding (Case et al., 2005, Brashers et al. 2002)

Use of internet was more for exchange of factual information than for social exchanges in Twombly et al.' study (2011) but findings in this study indicate internet used a lot for community support as well as factual information.

Pain (1998) : Parents used print material only to backup preferred personal communications with health professionals but in this study the parents' preference went to Facebook which was then backed by advice from health professional

This study exemplifies the competency theory developed by Gross (2005) to explain that people who have a low-level of skill are also lacking in the metacognitive skill to recognize their own incompetence and overestimate their abilities.

Limitations

Sample is purposive and convenience based

Selection bias

Nor a very proportional representation of ethnicities in Canada

No data on SES.

Did not include people whose first language is not English

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Thank you!

Questions?