Understanding the Experiences of
Persons with Age-Related Vision Loss in
Accessing and Using
Community Services and Resources

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Comprendre les expériences des personnes ayant l'incapacité visuelle à l'âge dans l'accès et l'utilisation des services et ressources communautaires

# Producer notes

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This document contains passages from the "Comment" option in the PowerPoint presentation. In this E-text document, they are inserted between the tags {Comments} {/ Comments}.}

# Special symbols

{<\_\_>} left right arrow; z notation relation

# Navigation links

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# Understanding the Experiences ofPersons with Age-Related Vision Loss inAccessing and UsingCommunity Services and Resources

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Comprendre les expériences des personnes ayant l'incapacité visuelle à l'âge dans l'accès et l'utilisation des services et ressources communautaires

Nicole Ahrens, Rachel Dinoff, Tiffany Huang, Shay-Lynn Smith, Julia Foster, Dr. Colleen McGrath, Dr. Dorothy Kessler

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**Désolée pour toute erreur**

J'ai utilisé Google Translate pour le français

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## Acknowledgements

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**Dr. Colleen McGrath** (collaboratrice)
* **South East Ontario Vision Rehabilitation Service**
	+ {Logo SOVRS} = {Logo Kingston Health Sciences Centre/Centre des sciences de la santé de Kingston} + {Logo Vision Loss Rehabilitation Ontario/Réadaptation en déficience visuelle}
* **Ontario Society of Occupational Therapists Research Fund** ($$)

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## Vision loss and use of supports

* Vision loss negatively impacts overall health, independence, and participation in occupation (Access Economics, 2012; Blaylock, Barstow, Vogtle, & Bennett, 2015; Brown, Goldstein, Chan, Massor & Ramulu, 2014)
* Many use informal (e.g., family) or formal supports in completing their daily activities (Blaylock, Barstow, Vogtle, & Bennett, 2015; Smallfield et al., 2017; Smith, Ludwig, Andersen, & Copolillo, 2009)
* Community services are a research priority for adults with ARVL (McGrath, Laliberte Rudman, Hand, Benjamin, & Corrado, in process)
	+ They want healthcare professionals to provide information

{Line break}

Incapacité visuelle et utilisation des supports

* L'incapacité visuelle peut avoir un impact négatif sur la santé globale, l'indépendance et la participation (Access Economics, 2012; Blaylock, Barstow, Vogtle, & Bennett, 2015; Brown, Goldstein, Chan, Massor & Ramulu, 2014)
* Les gens utilisent des soutiens informels (p. ex., familiaux) ou formels pour accomplir leurs activités quotidiennes (Blaylock, Barstow, Vogtle, & Bennett, 2015; Smallfield et al., 2017; Smith, Ludwig, Andersen, & Copolillo, 2009)
* Les services communautaires sont une priorité de recherche pour les adultes ayant une perte visuelle liée à l'âge (McGrath, Laliberte Rudman, Hand, Benjamin, & Corrado, in process)
	+ Ils veulent que les professionnels de la santé fournissent plus d'informations

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## Objective of the study

There is limited research on the range of supports used and clients' experiences in using these supports. Individuals may be using services and supports in innovative ways that could be shared with others, and importantly, identification of facilitators and barriers can both inform service delivery and guide program development.

**Research Objective:** Explore the current use of support by older adults with age-related vision loss, specifically:

1. Identify the ways informal and formal supports are being used to support engagement in desired occupations.
2. Explore the experiences of using supports, including the facilitators and barriers to using available supports
3. Identify ideal characteristics of supports

{Box}

**Application:** inform services + guide resource development

{/Box}

{Line break}

Objectif de l'étude

**Objectif de recherche:** Explorer l'utilisation actuelle du soutien par les personnes âgées ayant une perte de vision liée à l'âge, en particulier:

1. Identifier les façons dont les soutiens informels et formels sont utilisés pour soutenir l'engagement dans les professions souhaitées.
2. Explorer les expériences d'utilisation des soutiens, y compris les facilitateurs et les obstacles à l'utilisation des soutiens disponibles
3. Identifier les caractéristiques idéales des supports

{Box}

**Application: informer les services + guider le développement des ressources**

{/Box}

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## Methodology

* **Design:** descriptive qualitative study using conventional content analysis
* **Inclusion Criteria:**
	+ Older adults (65 years or older)
	+ ARVL
	+ Living in the community
	+ English speaking
* **Recruitment:** purposive sampling
* **Data Collection:**
	+ Phase 1: individual semi-structured interviews (completed)
	+ Phase 2: focus group (analysis phase)

{Line break}

Méthodologie

* **Conception de la recherche:** étude qualitative descriptive utilisant l'analyse de contenu conventionnelle
* **Critère d'intégration:**
	+ personnes âgées de 65 ans +
	+ avec perte de vision liée à l'âge (ARVL)
	+ vivant dans la communauté (i.e., pas dans un établissement)
	+ anglophone
* **Recrutement:** échantillonnage ciblé
* **Collecte de données:**
	+ Phase 1: entretiens individuels semi-structurés (achevée)
	+ Phase 2: groupe de discussion (en cours d'analyse)

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## Results

### Participants

* Sample size: 8
* Age: 68-96 years of age
* Sex
	+ F: 7
	+ M: 1
* Eye condition
	+ ARMD: 7
	+ Cataracts: 2
	+ Other: 1
	+ Unknown: 1
* Onset of vision loss
	+ Sudden: 3
	+ Gradual: 5
* Living situation:
	+ 5 live alone
	+ 3 live with others
* Residence:
	+ Apartment: 5
	+ House: 3
* Geographical area:
	+ Urban: 6
	+ Rural: 2
* Financial situation:
	+ "Good": 3
	+ "Fair": 5

{Line break}

Résultats

Participants

* Échantillon: 8
* Âge: 68-96 ans
* Sexe
	+ 7 femmes
	+ 1 homme
* Maladie oculaire
	+ DMLA/AMD: 7
	+ cataractes: 2
	+ autre: 1
	+ inconnue: 1
* Vitesse d'apparition
	+ rapide: 3
	+ lentement: 5
* Vit seul ou non
	+ seul: 5
	+ en famille: 3
* Type de domicile
	+ appartement: 5
	+ maison: 3
* Milieu de vie
	+ urbain: 6
	+ rural: 2
* Situation financière
	+ "bien": 3
	+ "passable": 5

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### Purpose of Supports Used

* **Community mobility/transportation**
	+ {Illustration not described}
* **Meal** (shopping, preparing, organizing)
	+ {Illustration not described}
* **Information management and correspondence** (e.g., mail, phone calls, keeping important notes)
	+ {Illustration not described}
* **Personal affairs / household management** (e.g., medications, cleaning, finances)
	+ {Illustration not described}
* **Emotional supports** (e.g., support grieving, provide ideas for adaptations)
	+ {Illustration not described}

{Line break}

But des supports utilisés

* **Déplacements dans la communauté**
	+ {Illustration}
* **Repas**
	+ {Illustration}
* **Organisation de l'information**
	+ {Illustration}
* **Tâches quotidiennes et domestiques**
	+ {Illustration}
* **Soutien affectif**
	+ {Illustration}

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### Barriers/Facilitators to Support Use

* **Personal circumstances**
	+ {Illustration not described}
* **Health and well-being**
	+ {Illustration not described}
* **Attitude**
	+ {Illustration not described}
* **Technology**
	+ {Illustration not described}
* **Availability of information**
	+ {Illustration not described}
* **Relationships with others**
	+ {Illustration not described}
* **How services were set-up (e.g., eligibility, application process)**
	+ {Illustration not described}
* **Environmental factors (e.g., distance, weather, familiarity)**
	+ {Illustration not described}

{Comments}

Established **routines, coping strategies**, ability to still drive, **financial resources** all **facilitated** use of various supports

Various **barriers** were identified including other **health conditions, family situation, financial resources, language barriers**, etc.

**Interviewer:** And when you did go, **did you find it helpful for you to talk to others with vision loss?**

**M:** Well to be honest, **probably not because my son was ill then.** And I couldn't seem to get away from him, he had cancer, darn old cancer. But I might now, a little bit, maybe.

**Low mood and lack of motivation** were identified as **barriers** to using services

There was that girl …… **She brought me back my magnifying glass and she brought me back my talking watch. But I was very depressed that day too.**

Use of supports was **facilitated by** a **positive attitude and motivations** (to maintain health, stay independent, engage in occupations, access resources)

**J:** "It's just like if you're not a person that picks away at things, you're not going to find it. **If you're somebody that makes one phone call and then gives up you're not going to get further ahead. I'm a nit picky type. I keep pursuing."**

Barriers included **technology literacy, limitations of adaptive technology, and non-adaptive technology**

I'd probably Google it. I Google lots of stuff. But **there's no point in Googling if you can't read it.** My daughters are very helpful that way. They Google a lot too.

**Attitudes of supports, quality of the relationship, and other personal and life factors** of the supports acted as **barriers**

I'm not expecting anybody to take me anywhere and not pay… I've got a daughter and I've got a son but they don't... like first it was "oh it's fine I'll take you there – not anymore". **I don't know, I felt like a burden.** I did…. I don't like putting them out, because they could say no to me. **But then I really don't want them doing something that they don't want to do, you know?** And I know I was one, that would say "oh yeah, okay, okay" and behind be like "okay why did I do it" you know? And I don't want them to feel the same way.

**Quality of relationships and reciprocated support facilitated** use of supports

"As far as my girls are concerned we have always helped each other. That's how they were brought up and have always been. **If they need something they'll help out and if we need something they'll (we'll?) help out.** Like I was saying with our generation you just figure out ways of doing things and it's normally through family help – **you scratch my back and I'll scratch yours** – not necessarily with money".

A couple noted ease of applying and access through discounts, but many participants listed barriers including **paperwork, eligibility, waitlists,** timing/coordination of appointments

**N:** When I was in hospital, they kept saying "you have to have more services, you have to have more services". I said "yeah, okay and okay". So you'd phone up and **[they'd] say "no I'm sorry we can't give you anymore [services]"….** They keep saying 'no, we're sorry, we're sorry." **You get to the point that you don't phone back I know I don't anyways.**

A couple noted ease of applying and access through discounts, but many participants listed barriers including **paperwork, eligibility, waitlists**, timing/coordination of appointments

**N:** When I was in hospital, they kept saying "you have to have more services, you have to have more services". I said "yeah, okay and okay". So you'd phone up and **[they'd] say "no I'm sorry we can't give you anymore [services]"….** They keep saying "no, we're sorry, we're sorry." **You get to the point that you don't phone back I know I don't anyways.**

Facilitators included close **distance** to supports, **familiarity** of the environment

**J:** I mean I don't like shopping so I don't shop much. When I go I'd like to go to a store where I know where the stuff is. So then I can go and find it.

Barriers included **winter** conditions (especially related to falls), **transportation** (e.g., bus routes), **distance**, lack of **familiarity** of environment or supports

**M:** … **when it's someone I don't know** [driving me], they don't always get as close to the door as I'd like. Like my friend, he drives around until he can get right to the door. And my neighbour has wheelchair parking so he can get close to the door. But some don't, so sometimes I have to walk longer distances, so I'm afraid of riding with people I don't know…. **I don't feel comfortable asking** "Oh please, drive around the block and try and get closer to the door," I don't feel free to do that."

{/Comments}

{Line break}

Obstacles/facilitateurs pour soutenir l'utilisation

* **Circonstances personnelles**
	+ {Illustration}
* **Santé et bien-être**
	+ {Illustration}
* **Attitude**
	+ {Illustration}
* **Technologie**
	+ {Illustration}
* **Disponibilité des informations**
	+ {Illustration}
* **Relations avec d'autres personnes**
	+ {Illustration}
* **Prestations de service (p. ex., admissibilité, processus de demande)**
	+ {Illustration}
* **Facteurs environnementaux (p. ex., distance, temps, familiarité)**
	+ {Illustration}

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### Availability of information

Nancy: Well I don't know what the cost of [CCTVs] are.

Interviewer: … who would you ask … to get more information?

Nancy: I don't know.

Interviewer: Okay, so you know that that kind of equipment exists but you're not sure how to go about getting it.

Nancy: No I saw it when I went to low vision clinic, that's where I saw it and I thought. Then when they told me push the dial, I did and I couldn't believe the amount of things I could see.

**Interviewer: So you don't have any place that's specific that you could go to that would be like 'what is the visual equipment' and they could show you?**

**Nancy: No, so I just forget about it.**

{Line break}

**Paraphrased:** I saw equipment that helped me see, but I don't know who to ask, so I just forget about it

{Line break}

Disponibilité des informations

Paraphrasé: J'ai vu du matériel qui m'a aidé à voir, mais je ne sais pas à qui demander, alors je l'oublie.

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#### Example: Environmental factors

Melvin: … **when it's someone I don't know** [driving me], they don't always get as close to the door as I'd like. Like my friend, he drives around until he can get right to the door. And my neighbour has wheelchair parking so he can get close to the door. But some don't, so sometimes I have to walk longer distances, so I'm afraid of riding with people I don't know…. **I don't feel comfortable asking** "Oh please, drive around the block and try and get closer to the door," I don't feel free to do that.

{Line break}

**Paraphrased:** I don't feel comfortable asking volunteer drivers to drop me off closer to the door.

{Line break}

Exemple: Facteurs environnementaux

**Paraphrasé:** Je ne me sens pas à l'aise de demander à des chauffeurs bénévoles de me déposer plus près de la porte.

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### Gaps in support

In an ideal world …

* Additional services
* More support for acquiring products (e.g., accessibility)
* Environmental factors
* Fewer discontinued activities

{Comments}

* **Additional services** (e.g., mentors, system navigation)
	+ Like if somebody could teach you, somebody who already has the experience – like with my piano teach, I learned from sitting next to him and he was blind. He made me realize that if I ever do go blind, I can still sit there and feel the notes and play.
* **Support for acquiring products** (e.g., accessible websites)
* **Environmental modifications** (e.g., public understanding)
	+ "I knew a lady who had a white cane and she was saying she had talked to somebody down the street at a bus stop or something and the girl said to her "You should have got a pink cane" and the lady said "Don't you know what a white cane means?" she had no idea. So I was telling **my daughter** that story and she **didn't know what a white cane meant. I thought everybody knew.**"
* **[Fewer] discontinued activities**

{/Comments}

{Line break}

Supports manquants

Dans un monde idéal …

* Plus de services
* Soutenir l'acquisition de produits (p. ex., accessibilité)
* Facteurs environnementaux
* Moins d'activités abandonnées

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## Discussion

### Information

* Many "wishlist" supports already existed
	+ Importance of providing valuable information

Langford: Different types of support identified in the literature including emotional support, appraisal support which is sometimes included in emotional support, tangible or instrumental support – actually doing things, and informational support

{Illustrations not described}

{Line break}

Discussion

Information

* Les supports souhaités existaient déjà
	+ Importance de fournir des informations utiles
* **Soutien affectif**
* **Tangible**
	+ Déplacements dans la communauté
	+ Tâches quotidiennes et domestiques
* **Informatif**

{Illustrations not described}

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### Role of the social and institutional environment

* Significant variation in experiences (i.e., positive vs. negative)
	+ Equity
	+ Diverse environment
	+ Importance of assisting people in managing interactions / engagement with supports and services unique to their world

{Chart}

**Bronfenbrenner's Ecological Theory of Development**

* Individual {<\_\_>}
	+ Microsystem {<\_\_>}
	+ Mesosystem {<\_\_>}
		- Exosystem {<\_\_>}
			* Macrosystem

{Line break}

* **Macrosystem**
	+ Attitudes and ideologies of the culture
* **Exosystem**
	+ Industry
	+ Social services
	+ Mass media
	+ Local politics
	+ Neighbors
	+ Social services
* **Mesosystem**
* **Microsystem**
	+ Family
	+ Peers
	+ School
	+ Health services
	+ Church
* **Individual**
	+ Sex
	+ Age
	+ Health
	+ etc.

{/Chart}

Source: Bioecological Systems Theory (Bronfenbrenner & Morris, 2006)

{Line break}

Rôle de l'environnement social et institutionnel

* Variation significative des expériences (c.-à-d. positives vs négatives)
	+ Équité
	+ Environnement diversifié
	+ Importance d'aider les gens à gérer les interactions / l'engagement avec des soutiens et des services uniques à leur monde

{Chart}

**Théorie des systèmes bioécologiques**

* Individu {<\_\_>}
	+ Microsystème {<\_\_>}
	+ Mésosystème {<\_\_>}
		- Exosystème {<\_\_>}
			* Macrosystème

{Line break}

* **Macrosystème**
	+ Politique
	+ Société
	+ Cultutre
	+ Économie
* **Exosystème**
	+ Voisinage
	+ Famille étendue
	+ Système scolaire
	+ Médias
* **Mésosystème**
* **Microsystème**
	+ Famille
	+ École
	+ Pairs
	+ Croyances
* **Individu**
	+ Sexe,
	+ Âge,
	+ Santé,
	+ etc.

{/Chart}

Source: Théorie des systèmes bioécologiques (Bronfenbrenner & Morris, 2006)

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### Application

We want to know how others teams / healthcare providers support clients in accessing services and using social supports

* Collaborate with clients to further find out what they want (focus group)
* Learn from other providers (you!)
* Share what was learned
* Program / resource development

{Line break}

Application

* Collaborer avec les clients pour mieux découvrir ce qu'ils veulent (groupe de discussion)
* Apprenez des autres fournisseurs (vous!)
* Partagez ce qui a été appris
* Développement de programmes / ressources

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## Questions?

What resources / processes are you using?

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{Line break}

Questions?

Quels ressources / processus utilisez-vous?

Julia.foster@kingstonhsc.ca

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