

Understanding the Communication Experiences of Patients with Intellectual and Developmental Disabilities in Healthcare Settings



Bever T.¹, Domingue O.¹, Evans C.¹, Krishnan A.¹, Le M.¹, Sarathy A.¹, Thompson R.¹, Vuong, R.Q.¹, Reilly M.², Everse S.¹
¹Larner College of Medicine at the University of Vermont ²Champlain Community Services



Introduction

Champlain Community Services (CCS) provides highly personalized support to Vermonters with **Intellectual and Developmental Disabilities (IDD)**. The Larner College of Medicine is partnering with CCS to explore the challenges faced by their consumers, particularly those who are non or minimally speaking in healthcare settings.

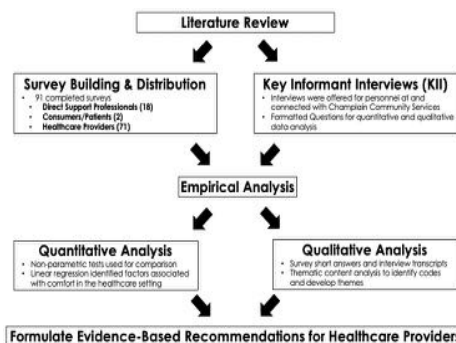
Challenges Faced in Healthcare Settings

- **Misconceptions** that non-speaking people with IDD cannot feel or express pain³
- Unfamiliarity of healthcare professionals with **ADA requirements**^{4,5}
- Disuse of **adapted pain scales**^{1,2}

Project Objectives

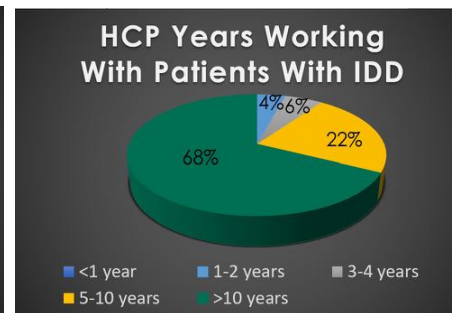
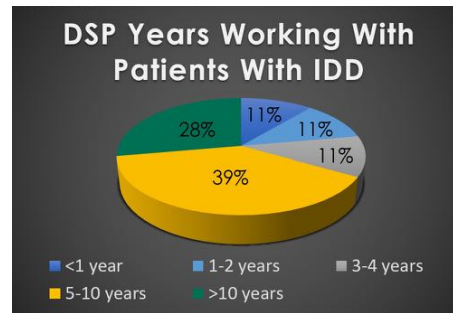
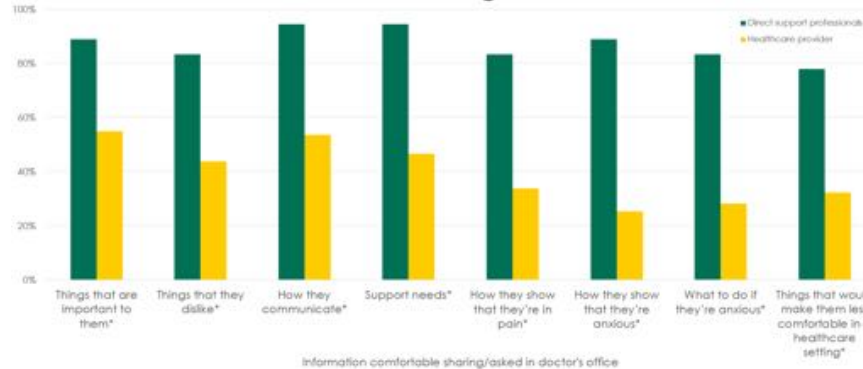
- **Gather perspectives** from healthcare providers (HCPs), CCS direct support personnel (DSPs), and CCS consumers on their experiences treating, supporting, and being patients with IDDs
- Create an **evidence-based model** for the patient, DSPs, and HCPs to bridge and ameliorate communication barriers

Methods



Results

Differences in Information Sharing Between DSPs and HCPs



Key Anecdotes in Support of a Patient-Centered Approach

Medical Jargon

"Sometimes I don't understand the **medical language**" (Individual with an IDD)

Need for Personalized Care

"It's actually **respectful** to establish how they [individuals with IDD] respond or communicate their needs around health [and] pain." (DSP)

Lack of Direct Communication

"The **doctor didn't know I was hurt** and wasn't listening... this is **my body... they don't listen to us.**" (Individual with an IDD)

Incomplete Understanding of Unique Needs

"It takes a **little bit longer** for us to register what is going on...give us time." (Individual with an IDD)

Discussion

The proportion of HCPs with greater than five years of experience working with patients with IDD is **significantly higher** than the proportion of DSPs; yet DSPs report communication challenges between HCPs and patients.

Communication challenges include:

- **Lack of assistance with...**
 - Treatment plan coordination
 - Patient portal and health insurance navigation
 - Medical jargon
- **Observed instances where HCPs showed a lack of...**
 - Patience for patient anxiety
 - Knowledge of patient communication needs
 - Inclusion of individual with IDD in medical decision making

Recommendations

- **Personalized patient info sheets:** general info about patient's life, preferences, communication style and pain expression
- **HCP upfront inquiry about pain** expression and communication preferences of patients with IDD
- Conversion of paperwork to **verbal interview format**
- **Increased HCP education** regarding IDD

HCPs must adopt **patient-centered communication approaches** to mitigate communication challenges and provide efficient and compassionate care.

References

1. Disability Data Digest. TheAccura. Published October 2, 2018. Accessed April 20, 2022. <http://www.theaccura.com/2018/10/02/disability-data-digest/>
2. El Mirayyan N, Eberhard J, Anstöm G. The occurrence of comorbidities with affective and anxiety disorders among older people with intellectual disability compared with the general population: a register study. *BMC Psychiatry*. 2019;19:166. doi:10.1186/s12888-019-2311-z
3. Kankkunen P, Sana P, Vainilainen A, Kuronen V. Pain assessment among non-communicating intellectually disabled people described by nursing staff. *Open Nurs J*. 2010;4:55-59. doi:10.2196/2010.04.005
4. Aggarwal N, Campbell BC, Resaklam J, Iezzoni LI. Communicating with patients with disability: perspectives of practicing physicians. *J Gen Intern Med*. 2019;34(7):1139-1145. doi:10.1007/s11606-019-0491-4
5. McCaffrey LB, Kaiser KS, Hasfield-Wolfe EM, Iyama F. Pain assessment in non-communicative adult palliative care patients. *Nurs Clin North Am*. 2016;51(3):397-431. doi:10.1016/j.cnur.2016.05.009