S A L N | Self Advocate Leadership Network British Columbia

Thinking About Language. Words Matter. Words Have Power.

The Self-Advocate Leadership Network's Journey Through Thinking About Language

August 2020

Created by SALN members and their Supporters

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Who is SALN? The Self Advocate Leadership Network of British Columbia

SALN is a Network made of self-advocates from leading organizations in the Lower Mainland and Vancouver Island. The majority of SALN members are part of provincial self-advocacy and advisory groups. SALN is aware and interested in the BC self-advocate movement. All SALN members are well established and recognizable.

SALN Vision:
- Together as one
- Community For All
- Equal People
- Learning from History

The SALN vision is what SALN wants for the disability community.

SALN Mission Statement:
- To promote a good life through positive and informed: actions, networking, and advocacy.

The SALN mission statement is what guides SALN. SALN and SALN members must follow the mission statement.

Who participated in this project…

SALN MEMBERS	SALN SUPPORTERS
Bryce Schaufelberger, President Mission Self Advocacy and Manager Self-Advocate Net	**Jill Glennie**
Dave Sherritt, Vice President BC People First	**Arlene Schouten**
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Our Introduction…The story behind this report

"Behind every word is a person" - author unknown

The Purpose of this report

- **To address how the system and service providers refer to people who use their services and deliver a report to Ross Chilton of Community Living BC. (CLBC)**
- **To share our report and the process we used to think about the use of language to keep this conversation alive.**

The Back story: One day during a social chat on the phone between Michael and Ross…Michael said to

Ross "I don't like the word client – it doesn't sound right…what do you think of the word client?" Ross said…" Can you find something better?"

And so it began…the challenge was brought back to The Self Advocate Leadership Network.

What We Did and Why

For years, people with disabilities have not had very much control over the way society "refers" to them. There has been a never-ending struggle for people to be heard and listened to. Over and over, we are asked to "come to the table", "be a part of a consultation", "asked what we think and our opinion" about language…but nothing seems to change.

SALN believes it is time to have a serious conversation and support ways to help people think differently…and think about supporting self-advocates and people with disabilities to lead the change in language that is imposed on them.

"Having positive control of your life requires language that empowers people. Being recognized and valued begins with mutual respect and how we are introduced, how others refer to us."…Michael Smull (The Learning Community for Person Centred Practices)

Questions we first asked ourselves…

Is language positive, respectful, meaningful, helpful, easy to understand, universal (the world would understand and use), common, ordinary?

Does it promote inclusion or create exclusion?

While keeping in mind…

- It would be so nice to just use people or person…but…
- The system (government, CLBC and service providers) need language and terms that reflect the people who use their funded services and supports because:

- o To ensure things are clear and the supports and services are provided for a certain group of people and not for anyone.
- o To help write policies, contracts, other documents.
- o To ensure things are not confusing.
- o To ensure funding goes to the right people and the right place.

- Is not dictating and imposing what we think is right or wrong. We want to be open minded based on people's experience, history, where they live – but maintaining the principles of decent language.   We understand language is different all over the world, but there are basic principles of respect, kindness and inclusion. We want to encourage and deepen understanding.

What we did…

- We had a meeting to discuss, share and educate each other on the history of language in the disability world.
- We were led through a series of exercises facilitated by Nolda Ware.
- We brainstormed a list of words and terms we hear (or see) people or organizations use to describe people with disabilities.
- Through discussion, small group work, debate – we worked together to decide what we like…and what we don't like…and what is ok and acceptable.   **And the reasons WHY…**
- We were serious and we had fun – some conversations had to be censored!

Honest conversations with SALN 😊

"This work is way overdue! Why is it taking so long to listen to people? We need to be asking people – what words (language) do you like and don't like when others talk about you? Asking people if they understand the language you use?   Stop using language people do not like or have asked the world to stop using. Stop inventing and using language that is made up by others and not by people themselves! "…SALN Member

Our favourite words and terms…and why…

"They build people up instead of tearing them down." …SALN Supporter

Through discussion, sharing and debate…these are the words and terms we liked the best.

The words and terms we agreed we liked the best	Why
People/person	These words actually describe who and what all of us are. We are no different than others and everyone has some kind of disability or barrier – even if it is unseen. When possible, can people please use these words. These words are the best; however, I know it is not descriptive enough for CLBC.
People with diverse abilities	I prefer people with diverse abilities because it states people first and that people have diverse abilities (gifts, strengths & valued contributors instead of disabilities.) People with diverse abilities is respectful. I like that this term was created by people with disabilities not by others. Grassroots. "**Language created by us not others**". It gave the people the power – not language imposed on them.

The words and terms we agreed we liked the best	Why
	It makes me feel like a human being with real feelings, hopes and dreams.

People we support
   ▸ **People the organization supports**
   ▸ **People CLBC supports**
   ▸ **The person I support**
	All humans need some kind of support in their lives. Everyone is supported.
	
	I like this because everyone needs support or some kind of help in different ways and they are people first.
	
	It is clear and common language used by anyone.
	Easy to say and easy to understand.
	
	I like person/people first but 2nd option would be people we support. Once again describing everyone as people 1st who may require support.
	
	When support workers describe us as people they support, I strongly believe that it causes us to be more confident, secure and valued.
	
	With this language, now you are allowing me to be happy, healthy and safe.

Person or people who receive services	A description and clear. Easy to understand. Person is used first. Positive and respectful.

The words and terms we agreed we liked the best	Why
	It tells people if we are part of a Community Living organization.

We recognize that certain terms need to be used in order to receive funding, we don't always like the term itself, but this is a neutral enough term that we like it.

This reflects people own the services that they are getting. |
| **People or person with a disability.**

People or person with a developmental disability. | Some people embrace the word disability – they do not see it as a negative but as a part of who they are as a human being – that it defines them as a person. People should not be judged if they want to use disability to define or describe who they are.

I don't look at this as a negative – it is just a part of me and who I am. It is what it is…

Being defined as a person first and not just by their disability. |
| **People who use wheelchairs.**
Person who uses a wheelchair. | Person first and respectful.

Describes the person or a group of people.

Easy to understand.

Straightforward without being offensive.

Sometimes it is important to describe |

The words and terms we agreed we liked the best	Why
	how a person moves around because they might need wheelchair accessibility – which is not always available.
Self-advocate	If people have a role as a self-advocate. But this word should not be used for EVERYONE. It depends on the person, not everyone advocates for themselves or is able to advocate for themselves. I like it because it is known that we are speaking up and we have power to change things and say how we feel. It lets people know we have a voice and should be heard.
Youth	This is a word used for anyone who is under the age of 19.
Student	This word is used for everyone if they go to school.
About where people live	**Why**
The person's home/their home. **The people who live at _____.** **The person I support in their home.** **The people I support in their home.**	These are all ways we use when talking about anyone. They are ordinary and inclusive. These statements refer to people as people. With these words I feel like I am an equal person – they emphasize person first, they sound better and they feel better.

About how people communicate **The words and terms we agreed we liked the best**	Why
People who communicate in different ways. **People who speak in different ways.** **People who don't use words to communicate.** **People who don't use words to speak.**	These are easy to understand and easy to say. They describe the person instead of labelling them. They are respectful. ALL PEOPLE communicate in different ways – so let's just describe it that way and honour people.

Other comments and thoughts about why we like these words and terms…

We are people first. We are people.

They recognize the person before anything else. They refer to people or the person first.

We believe in thinking and speaking positively instead of negatively.

I like these words because they are more positive than negative and sometimes descriptions can be useful in certain situations. (A description is different than a label!)

Words that are Universal are important. And could be used anywhere.

They are respectful.

They are easy to say, easy to understand.

Common and ordinary language.

There is less chance of them changing over time.

They make me feel like I am using respectful language. They do not focus on anything that is perceived or generalized as negative, demeaning or discriminating.

We are all people. We like these terms because it doesn't describe what is "wrong" with us, but rather, it describes us.

Words and terms we think are acceptable…they are ok…

Through discussion, sharing and debate…there were some words and terms that we felt were acceptable. We recognize that people use language in different ways…we tried to have an open mind. 😊

The Words and Terms we think are acceptable…ok…	Why
People who live with a disability.	This says the same thing as People with a disability. "I have a disability" – may be more invisible. "I live with a disability" – may be more visible or physical. Something people live with and need to manage – for example: "visually impaired, use a wheelchair, has seizures, has a heart condition." This describes what people live with rather than just being a label.
People who experience a disability.	People with a disability is one thing, but people who experience a disability is different – this might be temporary, but I live with it.

The Words and Terms we think are acceptable…ok…	Why
	This works for some people – and doesn't work for others.
People with lived experience.	This seems like respectful, ordinary, universal language. Just need to ensure people know what it means.

Some people don't know what this means. |
| **People/person supported.** | People supported only makes sense if used in the community living field.

It seems to be a "short cut" – can't people say "person I support – people we support" instead?

Be careful – this can easily turn into a disability label. |
| **People who are CLBC eligible.** | This term should not be used to describe people – maybe only in a document or contract.

It should only be used by CLBC or service providers to help people get services and supports. |
| **Person who operates a wheelchair.** | Some people who use wheelchairs prefer this term. |
| **Tenant or renter** | As long as these words are used for anyone who rents a room, apartment, townhouse – their home.

Why does tenant need to be used to describe people? The only person who should call me a tenant or renter is my landlord.   How about trying "the |

The Words and Terms we think are acceptable...ok...	Why
	people who live there, the person who lives there, the people who live in the apartment building."
People who communicate differently	I like people who communicate in different ways better – as "differently" sounds like I don't fit in. It says I am different than the rest of the world – I am an outsider.

Words and terms we don't like...and why...

"It is tough to see Self-Advocates frustrated and feeling disempowered because of the way people use language."
...SALN Supporter

It was not difficult to come to agreement about the words and terms we do not like.

The words and terms we don't like	Why
Client	For terms like client, service user, etc. I am not being served, I am getting supported, not serviced. I'm not a consumer, client, customer, etc. Last time I checked, we are people, we don't call ourselves clients. 'Client': I don't like this because it usually has a bad feeling to it when it is used by service providers.

The words and terms we don't like	Why
	Old, institutional language. Over used and has become a disability label.

Come on already! How long do we have to keep asking people to stop using this word!!!!

Stop calling us "clients!" |
| **Individual** | This is used a lot – but it still seems it is separating us from others.

It's a word not everyone understands or can say.

Over used, one size fits all, is starting to sound exclusionary – "us and them" message.

This has now become a label for people with diverse abilities. |
| **Supported individual** | A mouthful, a tongue twister!

This is just ridiculous!

Hard to say and don't know what it means.

This has now become a disability label.

It's a label – where is the word person or people? |
| **Participant** | It is hard to say and pronounce.

Another tongue twister! |

The words and terms we don't like	Why
	I know people who don't know what this means. WAY over used and is now becoming a negative term – or a term used for people with diverse abilities. Us and Them. It needs to go. Better is "person who participates."
Consumer **Customer**	What the heck does this mean!? Sounds like I am eating a hamburger and having a beer. It's sounds like I am a label – not a person. Who started using these silly words to describe people with diverse abilities? Ridiculous…
CLBC eligible	Where is the person? Once again, people first. I don't know what this means. If CLBC or a service provider wants to use this term, say "people who are eligible for CLBC services, supports or funding" - then it might be ok.
Service user/service recipient	What???!!!! No idea what these mean. Again – forgetting we are people.

The words and terms we don't like	Why
Special Needs	I don't want anyone to label me with special needs. What makes me more special than anyone else? Old school language. It makes people sound "needy."
Folks	Sounds like I am talking to my grandpa! Old fashioned. Sounds weird.
Person/people served, People we serve	Confusing, don't know what this means. When using "served" it sounds like supporters and organizations are "servants". Not very nice. Sounds like I am in a restaurant or a hotel! We understand some people and organizations think this is respectful – but there are better words and terms.
People who identify with a label People who are labelled	Don't use the word label please. Many people do not understand what this means.

The words and terms we don't like	Why
People with intellectual disabilities. People with cognitive disabilities.	What does intellectual and cognitive mean? Yuk – how many people know what intellectual means? Or how to say it? And knowing that people are calling you that and you don't know what it means? That is terrible… People without disabilities often suggest I use this, but maybe I would like to use a different word. I don't like anything clinical or that is social service language. Promotes the us and them attitude. Eg. intellectual disability. How did this language get so popular? Who invented this stuff? I bet it wasn't someone with a disability! Developmental or intellectual? Developmental disability – I am developing and learning. We are always developing – intellectual disability sounds like I am stupid or dumb. It does not sound nice and it sounds degrading. We would like to know where this term came from?
Person/people needing support	NEED sounds negative. It is better to say people wanting support. Or want and need support.

The words and terms we don't like	Why
Semi-independent	Unclear, vague, doesn't say anything about the person. Condescending. What does this mean? What people can do for themselves is different for everyone – so even independent is very unclear.
Job seeker	How about person looking for a job. Job seeker: just sounds childish! Stop calling us something different from other ordinary employment groups or services.
Challenged	Old institutional language. Has a negative meaning – focuses on weakness and issues. I don't like any terms that use "challenged."
High functioning, low functioning	We don't know what this means – and we want to know! Sounds gross. Some terms are just derogatory, rude. High functioning, low functioning – they're put downs, reminds me of the days of the institution. It is so hard to believe people are still using these demeaning words.

The words and terms we don't like	Why
Gifted	When I think of gifted people I think of geniuses. If it is used to describe people with diverse abilities – it separates us and becomes a label. Everyone has gifts and talents. Say I have gifts...not I am gifted.
Mentally disabled, mental handicap, mentally challenged, handicapped, people with mental disabilities	Just plain old disrespectful. No one should be called these names. They are one step away from the R word. They are offensive. Horrible language for anyone to use. They encourage people to judge me. If people call me these words, it makes me feel stupid. Very old institutional language. These words are a part of the past – there is no excuse if they are still being used.
Mentally R word**	**No comment needed!**
Disabled people, physically disabled	People or person first please. Old school language. It's not that hard to change up the way we say things – to be current, progressive and respectful.
Those guys, them, those people	I don't like these terms because it makes me feel like I don't fit in.

The words and terms we don't like	Why
	They sound mean and hurtful. They say we are not good enough.
	They are a form of discrimination.
	They are excluding and separating us.
Our guys, my guys, my individuals, my participants	No way – we are our own people. Nobody "owns" us.
	"My or our" sounds like ownership – no one owns anyone! People are not possessions.
	I am a person – not somebody's object.
	I don't "belong" to staff.
	This is Power over instead of Power with.
The wheelchairs	This is horrible – when I hear people say "I am with a wheelchair today or I am taking out the wheelchairs", it makes me want to cry.
IDD	What??? HUH??? No idea what this means.
Adult child	This does not make sense at all! How can you be an adult and a child at the same time?
	Can't mom just say "my 30-year-old daughter?"
Kids – when referring to adults	No comment needed!

Patients	ONLY if someone is in the hospital.
The words and terms we don't like **Using a person's initials instead of their names.**	**Why** We can understand if there are more than one person with the same name using the service. But why not say "John B.?" Sometimes we have to use this method for privacy reasons, but we prefer full names…at least first names.
Being called by our diagnosis – Downs, schizophrenic, deaf, blind, CP, mentally ill, etc.	It's rude to be called by our diagnosis. Demeaning, degrading, disrespectful. Forgetting the person again. Where is the human being?
About where people live	**Why**
Resident	Resident and tenant are fine if they are used properly and include everyone. Eg. The tenants of the apartment building, the residents of Surrey. Resident or tenant should be used as common, everyday language but not replace PEOPLE or PERSON - then it becomes a disability label. Resident is being used to describe and label people with disabilities. Especially for people who live in a group home. Instead of "the residents" try "the people who live in the group home." It is not a bad word itself, but it has been used to label people with disabilities way too much.

About how people communicate	Why
The words and terms we don't like **Non-verbal**	Not everyone knows what this means. This term is overused, has become negative and a label. It is not ordinary language – it is doctor language. This word should never be used to describe people. Person first please!! Non-verbal is a label and forgets "the person." See the other examples we like and please start using them.

A PARTICIPANT ON AN OUTING?

NO...JO-ANNE OUT ENJOYING A MUDSLIDE.

ARE WE "WHEELCHAIRS"? OR ARE WE PEOPLE?

Other comments and thoughts about why we don't like these words and terms…

"Us and them" – language that makes people different, separate and excludes us from others. Promotes the "us and them" attitude.

These words hurt all people with disabilities, no matter who they are.

Dehumanizing, devalues people. Patronizing, condescending.
Many are negative, disrespectful, demeaning, hurtful.

Implies we are not equal citizens.

Depersonalizes and objectifies the person: degrading and sounds like treating a person as an object or a thing instead of a human being. Such as "a wheelchair or a wheelchair user."

Some words many people do not understand or have trouble saying: such as intellectual disability, consumer, service recipient, participant, supported individual.

Deficit, challenged, limited, need or needs – focuses on what people can't do.

All these words and terms are negative, imply a dependency on the system, implies the person as being vulnerable, need fixing, are unequal.

They make me feel like I am devaluing a person. That I am saying you can't do …. You are less than ….

It makes me feel like I want to say a million other things about the person I am talking about to overpower the word or phrase.

It makes me feel uncomfortable.
A lot of these words are old-school. Some terms date back to the institutional days.

A lot of terms are not nice – derogatory – a historical thing – it sounds like an institution term.

Who came up with some of these ridiculous words!?

Some sound stupid.
Some are unacceptable.
Some are hard to say – some we don't understand.
Some of the words are confusing.
They make me feel bad and mad.
These words are hurtful and disrespectful.
These words are mostly not used anymore.

What are they implying? Some words are too vague and I don't understand why people can't just use my name instead? Why does it have to be brought up to begin with? Why do people with visible disabilities have to be called something to begin with?

Not too sure about these words and terms…we need to do some more thinking…

There were some words and terms we were not too sure about and thought we could talk about some more…things to think about…people to ask…

Not too sure about these words and terms	Why
Individual	This word is best used in everyday conversation as an ordinary word – not a label to be used to describe people with disabilities. Not to be used by the system, service providers or staff to describe people with disabilities. **See above section about what we don't like about this word.**
I have autism versus I am autistic	The words and terms should be up to people as to how they describe themselves, without judgement – eg. I am autistic, I have autism…it should be up to each person. We need to ask people what they prefer!
People who are blind,	Most people appear to prefer people who are visually impaired or people with low vision. Especially if they can see a bit. People who are legally blind – this makes more sense if they cannot see at all. I may tell people "I have trouble seeing or I can't see very well or I can't see." Describing myself works well.

Things we have thought about…comments, thoughts, ideas, questions…

"Your words, attitudes and actions impact my life more than my disability." …Disability is Natural website

How we think about people is reflected in how we talk about people.

Words are powerful.
We need to be careful what we say.
Language is so important – it shows how we treat people.

Words can be hurtful - the way they are being presented can be very discriminating.

People often speak before thinking on how words can affect the person.

Some words and terms that started out as respectful – with good intention…that over time shift and then become negative or an "us and them" meaning. So, we have to always keep looking at language and words.

How, as citizens we are all viewed as people first, either by their name or as a person not by their disability or whether or not they are dependent on a system.

Real people with different ways of living. Real human beings with their own real lives.

Try to teach our communities that we are citizens first.

When we are offended by a word or term, we can take the opportunity to let people know…and tell them why. We can offer alternatives.

There are lots of labels out there.

It is good to think about how words matter. It doesn't have to be complicated.

It is interesting how some words offend some people but not other people.

We can't make everyone happy but we have to try educating people.

Language is always changing, so this work and thinking needs to be done on a constant basis. If you keep having to fight for something, you start to lose interest…it's tiring and you learn to go with the flow. It is what it is. It's sad.

Sometimes you just grow up with a term and you just get used to it but I didn't always think that the term was wrong or anything. But it's not a term that you normally hear. People who come from different parts of the world have different terms…different language.

Questions that we came up

How would you feel if people used these terms to describe you?

How do we encourage everyone to really understand the importance of language?

How do we educate people? Language is something we hear, what we grow up with. What we hear growing up with can shape your thoughts and how you view yourself and others. Language impacts everything: how we learn, act, interact with others, impressions of others. Language is constantly changing, even if you don't mean to be offensive, you might be. It's a very fine balance – people need to constantly learn and change.

How to we help make changes – in a positive way – and not be the "language police"? People shut down or get defensive or feel bad…and then there is no opportunity for changing things. How do we respectfully help educate people? Help people be more aware of the impact of the language they use?

Who decides what language is the flavour of the day? Is it professionals or is language created by the people affected by the language? This seems obvious…but is it?

Why can't we keep it simple? Why do so much overthinking? It is really about respect and common sense. Rule of thumb – use people/person first before the rest of the words you use. Ask the person what they prefer.

Our Principles

Thinking about what we learned…

What can people keep in mind about language.

- Ask people what they prefer.
- Ask people what words and terms they like…and don't like.
- Ask people if they understand the words and terms you are using.
- Ask people if they are easy to say.
- Try to use the person's name as much as possible.
- Try to use the word person or people as much as possible.
- Ask yourself, are the words you use positive, respectful, meaningful, helpful?
- Ask yourself, do the words you use promote inclusion or foster exclusion?

HOW WE THINK ABOUT PEOPLE IS REFLECTED IN HOW WE TALK ABOUT PEOPLE.

How can we keep this conversation alive? Next steps…

Our world has not done a very good job of listening to people…and then acting on what they hear.

Now that we have started this conversation, we feel it is important to keep it alive. Figure out ways to support positive change.

WE CAN'T
GIVE UP…NO
MATTER HOW
LONG IT
TAKES…

Supporting a change in language…our ideas about how to keep this conversation alive.

Request an official letter/response back from Ross after report is delivered.

After delivering the report to Ross:
- Do a SALN News Sheet about the language report.

Share the report with everyone – the public, organizations, groups and all our networks such as:
- All Community Living organizations, AccessED, colleges, universities, schools, Family Support Institute, Planned Lifetime Advocacy Network (PLAN), The Learning Community for Person Centred Practices, BC Disability Caucus, BC CEO Network, Health Services for Community Living and Health Care organizations, Mental Health organizations, Disability Alliance, Inclusion BC, Family Support Worker Network, Home Share Provider Network, all our allies.
- Other Self Advocacy groups.

Create a zoom presentation of our language exercise for professionals such as

doctors, CLBC, Service Providers, people with diverse abilities, Direct Support Staff, Self Advocacy groups, families, Board of Directors, Teachers Pro D day.

Take the exercise to self advocate conferences. Including Inclusion BC.

Call for stories about language (theme) for Self-Advocate Net.

Send in for the next CLBC magazine.

Include in the Welcome Workshops.

MEDIA BLITZ! Newspapers, radio, television!

Share on websites and Facebook of allies and supporters…PLAN, IBC, UNITI, CLBC, ESATTA, BC People First, People First Canada, First Nations groups, GovBC, SAN, government employees, community centres and groups, Revenue Canada, all departments federal and provincial.

SALN Facebook – weekly, fun, language memes – call it "Monday Memes."

Our Recommendations…we suggest…

- Based on this report, help us keep this conversation alive.
- We hope that people try to make an effort to keep our principles in mind.
- Ross to send a copy to all CLBC offices and Service Providers.
- CLBC staff and service providers use this report as part of their training and orientation material for all staff.
- Share the report to help educate and support health care professionals in regards to language.
- The Community Living sector (CLBC and Service Providers) use this report to work towards changing the language in policies, reports and media.
- Recommend to CLBC that this report and topic is added to the Welcome Workshops that will be shared by the self-advocate on the Welcome Workshop team.

"**Change begins with ourselves. To create a better world we must think and act differently. Each one of us can help bring about the world we want to see – a world where our diversity is cherished and our equality is respected.**" **– from the Citizen Network Website.**