

inform yourself about what's happening at the CPMB-Cerebral Palsy Association of Manitoba!

CPMB Update

It has been awhile since the newsletter was released. We have been busy, so let me take



the opportunity to update you all. First, our logo. The old one had been around for at least 25 years, thanks to UPhouse we have a new design and an updated logo. We will be

slowly be changing from 'CPAM', (another organization uses this), to CPMB (Cerebral Palsy Manitoba). We have purchased this domain name and we will transition to using CPMB exclusively.



Our plan is to update the logo as we change the marketing items, for example the

new look for 'Inform'. However, we still have the old logo on signs, banners and other materials, so we will be seeing a mix of items for the next few years. Second, I have enclosed a very important survey in with the newsletter. I am hoping that you fill it out, for two reasons. Firstly, I need the information for the LOCKED OUT OF LIFE Campaign and the human rights case, we need to show the systemic nature of the case and that it just doesn't affect Amy and Tyson. Second is that I want to know about your housing needs and planning for the future. The Association has hired two individuals, Margy Nelson & Shelley Betton, to do a feasibility study on developing accessible, affordable housing for our members in the next few years. It is very important that we develop a clearer picture of your situation and dreams, and how we can be a partner for change.

If the feasibility study comes back to the Board of Directors with a clear path forward, we will have an evening meeting to get ideas and to move the process along.

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CP MR

www.cerebralpalsy.mb.ca



@CerebralPalsyAssociationOfMb



@CerebralPalsyMB



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Direct line 204-982-4842 Toll free 800-416-6166 Fax 204-982-4844

Email office@cerebralpalsy.mb.ca

903 - 213 Notre Dame Ave. Winnipeg, MB R3B 1N3

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Our ultimate goal might be to have a capital campaign and build a building. PLEASE FILL OUT THE SURVEY!

Third, it was a very busy summer, I was on the steering committee for the Disability Matters Vote campaign.
THANK YOU for your participation, your action, and your support. The campaign did make the political parties listen! It was great to see action across the whole province in every riding, and viewed and discussed by thousands of Manitobans.

As part of the campaign I did have the opportunity to meet with all the party leaders and voiced our message that, "Who Matters – We Matter"! If we do not keep the pressure on government we will slide back. I am working with Barrier Free Manitoba, consulting on reforms to EIA, and keeping the government on track for their promises.

In the newsletter you will see that we were active in giving out grants, having workshops, events for members and having fundraisers for the Association. We had a series of workshops on mental health called "Filling up your Mental Health Toolbox". In partnership with Canadian Council on Rehabilitation and Work (CCRW), CPMB held an evening for finding employment

on job search and accommodation. In the summer, we hosted a night out at a Goldeyes Game, and explored our creative side with professional artist and instructor Colleen Leduc.



If there is an activity or event that you want us to try to please let me know!

As you know, CPMB has partnered with the Society of Manitobans with Disabilities and Rehabilitation Centre for Children's LIFE program to bring you recreational programing, such as Boccia, Social nights, and programming in Westman. Please keep an eye out for more dates in the New Year!

I met with some of Cerebral Palsy Associations across Canada in St. Jean QC in early

October. The
Associations across
Canada are working on
developing a national
organization or an
affiliation structure
for all of us to work
together on a national
scale. We are looking
at developing best
practices, partner on
research, and talk











to government on policy, like Bill 81 – The Canada Accessibility Act. We also heard from researchers from Laval and McGill Universities. We are always looking for partners and good outcomes. These talks are ongoing and I will keep you all in the loop. m

CPMB BRAND GOAL – Cerebral Palsy Association of Manitoba – CP Proud.



Our dream is to get to a place where a cerebral palsy diagnosis is celebrated – and we're willing to battle with government, gather a loud and proud community, operate lean, and drum up long-term partnerships and fundraising dollars to get there.

If we want research done, we have to fund it. If we want better supports for adults with physical disabilities, we have to demand it. That's why it's a good thing our members are used to powering through challenges to get things done.

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Westman News & Notes

Our Westman Chapter been busy also. On October 5th we held our family retreat with members from all over Western Manitoba. During the day we hosted two speakers. Suzanne Swanton came from Continuity Care, and she explained the Registered Disability Savings Plans (RDSP) and reviewed the benefits of the RDSP. Second, we had Chris Rootsaert from TenTen Sinclair speak about looking for housing in Brandon and explaining what supports are out in the community to help members live independently.

We had a great dinner of chicken, ribs and delicious cheesecake, where members shared stories

shared stories and met each other. A huge highlight was being entertained by 'The Bubble Man', who delighted everyone with soapy fun.

Mr. Paul McGregor in Brandon had an art show, to present his art. Paul, a member of

the Association, donated the proceeds from his art sales. m





Making a More Accessible Community

The Cerebral Palsy Association Westman Committee was able to donate a third set of doors to create a more accessible environment for wheelchair curlers in Brandon. The Cerebral Palsy Association gave a grant to the Keystone Centre in Brandon to add two sets of accessible power door openers. Though accessible doors may seem like a part of life for some of us they are very much appreciated by the curling athletes.

"I think the addition of the new doors is wonderful," says Ryan Sturgeon, Chair of Brandon Wheelchair Sports & Leisure. "It's actually breaking down some barriers, because it's hard for people when they have mobility concerns or disability to go out to events, and having things made more accessible – having the environment made more accessible – is really encouraging, and really promotes an all-inclusive atmosphere and attitude that is really important to encourage people to come out".

We face barriers every day, often silently. Having a voice and visibility in the community is so important as we continue to prove that we belong in every space and every aspect of society. The new doors at the Keystone is another example of how our Bike Race and the funds raised through it continue to change the lives of people in our community.

The funds were donated to the CP Association through the partnership with the Brandon Firefighters Campout Campaign. Thanks goes out to those brave and generous men and women.



Pictured (from left): Chris Brandon – Curler, Ken Gill – Curler, Jeff Schumacher – Keystone Centre, Tom Czerkawski – CPMB, David Kron – CPMB, Lori Nevins – Wheelchair Curling Volunteer, Gilbert Perez – Curler.

Our 45th Birthday

Our 45th Annual General Meeting – 45 years of the Cerebral Palsy Association of Manitoba. Who would've thought we would make it this far? Thank you to all the members, volunteers and board members who have made 45 years of CPMB possible. My biggest fear is that I will plan an event and no one will show up! You keep showing up, so thank you.

Our birthday party was awesome! It was great to see over 45 members who came out to help us



celebrate. Thank you to Susana, who cut the cake into pieces using her protractor! We were all glad to have a very equal piece.



Byron Williams from the Public Interest Law Centre gave us an update on the 'Locked Out of Life' human rights complaint. The complaint will be going forward. The

campaign which goes along with the "Locked Out of Life" complaint has won multiple advertising awards, two provincial awards and two national awards. It has increased the conversation around independent living in the community and is reinforcing the fact that "all of us are stronger than one of us".

Bill Muloin - SMD's Leisure and Sports Coordinator spoke about the different programs that CPMB has supported and/ or had participants in. Such programs



include: Dance, Curling, Sledge Hockey, Wheelchair Basketball, Power Wheelchair Soccer, and Boccia Ball.

Matt Solvason, Treasurer of the Board, went over some of the most important parts of the 2018-2019 audited financial statements for us. A quick overview shows:

> Revenue \$413,614.00 Expenses \$387,772.00 Surplus \$25,843.00

As our 50th anniversary is fast approaching if you have any ideas of what you would like to see and or do feel free to let me know. **m**



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CPMB Update

When I started at the CP Association, I asked these questions:

HOW many people in Manitoba live with Cerebral Palsy?

WHERE do you live?

As one of our research projects, CPMB asked the Rehabilitation Centre for Children to do a chart review of their patients.

Here are some of the results:





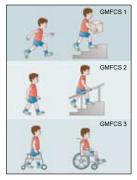
Services for Children and Youth with Cerebral Palsy at the Rehabilitation Centre for Children

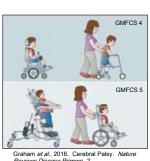
The Rehabilitation Centre for Children (RCC) in Winnipeg is a community-based health centre that has many programs and services available for children and youth with Cerebral Palsy, including Assistive Technology Clinic, Child Development Clinic, Feeding Clinic, Neonatal Follow-Up Program, Orthopedic Clinic, Orthotics, Recreational Programming, Spasticity Clinic, Specialized Communication Resources for Children, Spine Clinic, and Therapy Services (Occupational Therapy, Physiotherapy, and Speech Language Pathology)

We did a research project to find out how many children and youth with CP receive services from RCC, where they live, and their Gross Motor Function Classification System (GMFCS) level

What is the GMFCS?

- It was created at CanChild in Hamilton, Ontario
- It describes gross motor skills (like walking) using 5 levels
- It gives clinicians and families information about what a child can do, and what types of equipment or mobility aids a child may use in the future





Graham et al., 2016. Cerebral Palsy. Nature Reviews Disease Primers, 2.

Where do our children and youth with CP live?



Out of every 9 children and youth with CP, how many have each GMFCS level?







in in



Why is this information important?

- We are working with our therapists and clinicians to make sure every family knows their child's GMFCS level
 - Knowing this helps families plan for the future, for example, by knowing what types of equipment their child may need later in life
- We can better plan what services to offer families if we know how many children and youth use our different programs and where they live
 - For example, to offer services outsides of Winnipeg
- Knowing how many children and youth with CP we see and what services and equipment they use will help us plan future research projects







This project was conducted at the Rehabilitation Centre for Children in SSCY Centre, and was funded by the Cerebral Palsy Association of Manitoba (CPAM). If you would like more information about this project, please contact the RCC Research Coordinator Jessie, at (204) 258-6717 or jshea@rccinc.ca. If you would like more information about CPAM and their services, please contact their Executive Director David, at (204) 982-4842 or davidk@cerebralpalsy.mb.ca.

Prize Day 2019

It all started with a dance: a performance from the All Abilities Dancers and Studio Singers, under the auspices of choreographer and dancer, Brenda Gorlick. The troupe including eight of our members practice

and perform throughout the year but it was a first for one of our events. The





performance moved the audience to tears and hearty applause.

CPMB's fifth annual Prize Day, held at the GWL Conference Centre, 100 Osborne Street North celebrated the loyalty of the Association's sponsors, volunteers including our board, our captains and cyclists who are our major fundraisers. Canada Life, formerly Great-West Life has been the Stationary Bike Race's presenting sponsor for thirty



years. This year, the Great-West Life team led by captain Chad Fowlie topped the charts in cycling 358.16 km. and raising a record \$48,4888. Wow!

Prize Day gives the Bike Race organizers David Kron and Sarah Yates-Howorth the chance to thank all of our loyal sponsors, captains, cyclists and fundraisers, as well as our volunteers. Without your work, the Race could not succeed.

The Smith family's team Ryder's Riders came in second for their fundraising efforts; IG Wealth Management led by co-captains Keith and Mitch Potter came in third. Though we applaud these successes heartily, none of the other teams' amazing efforts are dismissed. This was our best year ever, thanks to all of you. We raised \$230,324.68 which enables the Association to give out more scholarships and equipment grants. Already we have more requests than we can currently meet but the Board and ED David Kron continue to budget and process as many applications as financially possible.

Nor are individual fundraisers forgotten for their efforts. IG Wealth Management's Todd Asman took home a glorious hand-blown bowl by Bonnie Heath. Mitchel Potter took home some Goldeyes' tickets, thanking us graciously with the support of his I-Pad. The Ehnes family Rebecca, Nathaniel with babe in arms and David also enjoyed the



Goldeyes over the summer, with our help. Finally, Kathy Bernard, our inveterate world scientist and team captain was

presented with some Manitoba Chamber Orchestra tickets. We know Richard and she enjoy both music and cycling.

Red River Coop has been a proud sponsor of the Race for the past year, with their contribution increasing yearly. In

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collaboration with CPMB and Freedom Concepts we literally doubled our assistance. Jenny and

Jessica Kowalson are identical twins and when you meet them, you do a double take because although they look so alike. However, their lives they are very different. Jennifer lives in her own apartment, works in city schools as an educational aide and works in the summer for the Rehab Centre for Children. To facilitate this work, she needed a bike. Doug Wiebe, CEO of Red River Coop proudly presented her with a custom-built Freedom Concepts three-wheeled bike. Things are set to change for Jessie too. We presented her with an I-Pad Pro to facilitate her communication through texting, email and speech.

"I've been speaking up for my sister for 26 years but this is a game changer for us both," Jen told a captive audience. "Her grin tells me how excited she is at this gift. I know Jessie; this is just the beginning of what she is going to share with us all."

As invited guests and proud parents, Warren and Helen Kowalson couldn't contain their glee.

The Wellness Institute has hosted the CPMB Stationary Bike Race for more than a dozen

years. Board chair, Franck Blandigneres presented them with one of the limited-edition pedestal bowls by ceramicist



Valerie Metcalfe. As Karin Whelan said, "the Wellness Institute is geared to helping individuals optimize their health, whether through rehabilitation, disease prevention or enhancement of their health outcomes. The CP Bike Race is our way of showing support to an organization, which encourages the mental and physical activities of its members and giving back to the community."

Finally, we honoured a family who has faithfully ridden for the Bike Race since their student days at St. Paul's High School when teacher Larry Franz suggested they enter a team. Since then, Matt, Jeremy and Tommy Semchyshyn have all captained teams from St. Paul's High School, St. Paul's College and

various alumni teams, working closely with the Bosc family. Larry Franz presented them with one of Metcalf's



glorious bowls and, in turn was surprised when David Kron presented him with a bowl of his own. Thanks Larry for all of your efforts, continuing through your involvement with the Pit Crew. It takes families like these to keep the race running wild and free and fruitful.

My final thanks go to my loyal opera companion and faithful friend, Linda Freed. When I shared with her my desire to raise funds for a performance by the All Abilities Dancers and Studio Singers, she graciously offered to help. Linda Freed underwrote half of all Prize Day costs, including food and photography. Thank you, Linda.

Party at Fort Gibraltar

St. Boniface's replica Fort Gibraltar hosted our first Know No Limits mid-summer feast on Thursday, July eleventh. After everyone was greeted by organizers John Wardell, Wayne Terry and Erin Smith-Skulimowski of the Western Fashion Group (co-sponsors for the sparkling event), guests visited volunteer Fire Fighters posing for shots or tried hatchet throwing with a Fort volunteer. Others enjoyed conversation and a pre-dinner drink.

The Fort interior sparkled with black-and-white table linen and spectacular white flower arrangements of hydrangeas and roses. Guests' round tables were surrounded on two sides by a host of amazing silent-auction items. John and Erin had collected a remarkable array of prints, leather goods, gift certificates and other beautiful and exotic objects d'art, generously donated by WFG clients and friends, which tempted us all to buy tickets. The event welcomed a whole new crowd of supporters for the Cerebral Palsy Association of Manitoba.

Fort Gibraltar was a picturesque setting for the party organized by John Wardell and Wayne Terry; (WFG is also a sponsor of the Stationary Bike Race). A light show and deejay dazzled and entertained. The sumptuous four-course dinner, featuring local ingredients, was enjoyed by more than a thousand guests. Comedian Big Daddy Tazz brought his wit and his son Tyler to urge folks to "empty your wallets for a good cause". His humourous take on life as a comedian

and as a family member had the audience listening, laughing and following his directive to contribute. The event raised over \$23,000 with its combination of sponsors, donors,

ticket holders and participants in the silent auction.

Mayor Brian
Bowman dropped
in; Senator Pat
Bovey stayed the
night and enjoyed
the dinner. Scott
Smith spoke
eloquently, giving



inspiration to all of us living with CP and urging us to vote. The video Locked Out of Life brought tears to many people's eyes. Fireworks punctuated the night as we all drifted home. Others danced the night away.

ALL CHARITIES CAMPAIGN - PROVINCE OF MANITOBA

This system provides current and retired employees of the Manitoba Government and its affiliates with a convenient method of giving annually to registered charities of their choice. These donations can be made through payroll deduction. All you need to do is request that your

donation be directed to Cerebral Palsy Association of Manitoba (Charitable Business Registration No. (10690 4212 RR0001). The CPMB is listed as [C040] in the All Charities Campaign Catalogue. See the online catalogue at http://www.allcharitiescampaign.ca/catalogue.html#C

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Seeking Personal Care

Samantha Mitchell, a member of the Cerebral Palsy Association of Manitoba is requesting an able-bodied female to attend Saint Benedict's monastery and retreat centre with her from August 11-14, 2020. The location is in West St. Paul.

Seeking female willing to do personal care and use the Hoyer lift. Must also be willing to help with craft projects, games and go for a nature Walks. Etc.

All accommodations and food are free of charge to the attendant. In addition Samantha's Attendant Will receive \$1400 for assisting her over this three-day time span. The attendant will also receive at least a one-hour break for a day and sometimes longer.

Saint Benedict's is a quiet and respectful environment. A person does not have to be religious to stay there. The attendant is not expected to go to church with Samantha.

Anybody who is interested should **contact** Samantha at 204-793-9605 by February 1, 2020.

CPMB Sales Corner

WALKER FOR SALE Interested? Call Larry @ 204-505-2450





Thanks for your Support

THANK YOU FOR ALL FOR SUPPORTING CPMB!

Cerebral Palsy Association Members Government of Manitoba – All Charities Campaign

City of Winnipeg Charitable Fund (Funded by Employees & Retirees)

Dr. Darcy Deacon Medical Foundation Brandon Jeans Day Participants

Mr. Paul McGregor

Brandon Firefighters Camp-out Campaign

Dreams Take Flight – Winnipeg

Field of Dreams – Winnipeg Goldeyes

Western Fashion Group

Manitoba Hydro

Starbuck All Charities

The Prairie Dawn Foundation

Linda Freed

Tracy Taylor -

Andrew Malo Memorial Scholarship

Queenston School – Freezie Day

Rural United Way – Morden & District

Rural United Way – Winkler & District

In Honour of Brooklyn

In Memoriam – Todd Bullee

In Memoriam – Carrina Selinger

In Memoriam – Ms. Bonas

In Memoriam – Mr. John Willcock

In Memoriam - Mrs. Joan Speirs

In Memoriam – Paula LePape

Red River CO-OP

Westman Group

Canadian Tire Store #286 – Brandon

Qualico – Acts of Kindness Grant

BOCCIA FOR ALL

FOR WHO?

Intro to Boccia!

Come out and play the game.

All abilities welcome!



WHAT?

You are invited to an intro to **Boccia**, (/botʃə/ boch-ə) a precision ball sport, similar to bocce. The sport is contested at local, national and international levels, by athletes with physical disabilities. It was originally designed to be played by people with cerebral palsy but now includes athletes with other various abilities. In 1984, it became a Paralympic sport, and in 2008 was being practised in over fifty countries worldwide.

WHEN and WHERE?

Thursday, October 10th, 2019 Thursday, November 14th, 2019 Thursday, December 12th, 2019 Thursday, January 9th, 2020 Thursday, February 13th, 2020 Thursday, March 12th, 2020 Thursday, April 9th, 2020 Thursday, May 14th, 2020 Thursday, June 11th, 2020

TIME

LOCATION

from 6:30 pm to 8:00 pm

Sergeant Tommy Prince Place 90 Sinclair Street Winnipeg, MB R2X 1X1

FOR FURTHER DETAILS, PLEASE CONTACT:

David Kron 204-982-4842; davidk@cerebralpalsy.mb.ca



Rehabilitation Centre for Children

1155 Notre Dame Avenue Winnipeg, MB, Canada R3E 3G1 Tel: (204) 452-4311 Fax: (204) 477-5547 www.rccinc.ca







Manitoba Cerebral Palsy Sports Association

The RBC Therapeutic Recreation and Wellness program is part of RCC's LIFE program, and is generously funded by the Children's Rehabilitation Foundation and their donors. For more information on their work with families and children with special needs, visit their website at www.crf.mb.ca



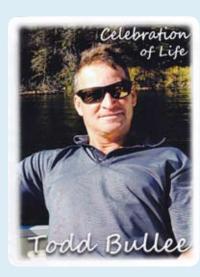
it's about ability"



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In Memorium: **Todd Bullee**

The Cerebral Palsy Association and the Brandon community lost someone special this spring. Todd was an avid supporter of the CP Association. For many years he was a rider and volunteer at the Westman bike race. Todd



brought his cheerful presence and helping hand to everything he was involved in. Giving back to the Community was a lifelong passion of his. He will be missed. Our condolences go out to his family and friends.

THANK YOU WINNIPEG! CYCLISTS RAISED OVER \$230,324



After 30 years, the CPAM Stationary Bike Race still rocks. 50 captains with teams of 14 cyclists raced to raise over \$230,324. Funds help the Association raise awareness, fund research, undertake advocacy and work to make the lives of 2500 Manitobans, living with CP, just a little bit easier.

THANKS DONORS & SPONSORS

- Great-West Life
- Assurance Company

 McDonalds Leila
- The Wellness Institute
- Taylor McCaffrey LLP
 Saikel Indoor Cycle Studio
- CBC Radio-Canada Manitoba

 • Western Fashion Group
- Dairy Farmers of Manitoba
 Winnipeg Blue Bombers
 Freedom Concepts Inc.
- Genumark InMotion Network.
- Physiotherapy Clinics

 McDonalds Southdale
- Red River Co-op

- Winnipeg Free Press
- Steingarten & Company LLP, Chartered Professional Accountants & Business
- Advisors
 United Fire Fighters of
- Winnipeg, Local 867
 Nancy Krahn, Avon
 Marie Birch
- The Canister on Osborne Bonnie Heath, Gypsy Soul Glass, Heather's Hustlers
- Rick Tucker, Bake Extraordinaire, Red Rive
- Coop Light Visions Katherine Buck and Glen Salzman, Montreal









APPROXIMATELY 50,000 PEOPLE IN CANADA LIVE WITH CP • DONATE AT CEREBRALPALSY.MB.CA

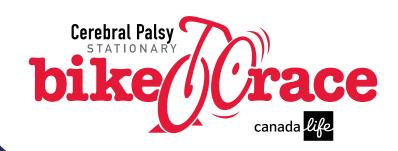




27[™] Annual Westman Stationary Bike Race



SAVE THE DATE SATURDAY MARCH 21ST, 2020





SAVE THE DATE SATURDAY MARCH 14TH, 2020

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Direct line 204-982-4842 Toll free 800-416-6166 Fax 204-982-4844

Email office@cerebralpalsy.mb.ca

903 - 213 Notre Dame Ave. Winnipeg, MB R3B 1N3

CPMB Members Demographic Survey

The Association has contracted Margy Nelson and Shelley Betton to do a feasibility study on developing accessible, affordable housing for our members. Margy and Shelley are gathering data in order to "build a case" to the Board of Directors both private and public funders; the completion of this survey will demonstrate the "need".



SURVEY DEADLINE: DEC 6TH. YOUR ATTENTION TO THIS SURVEY IS GREATLY APPRECIATED.

Complaint. So please fill the survey even if you are satisfied with your housing situation. I can send this in alternative formats if requested.

Please fill out survey and return in self-addressed envelope – Please keep it anonymous.

Survey questions for adults with CP - age 18

We are also sending out this survey to determine

Survey questions for adults with CP - age 18 (if you are turning 18 in 2020)

the systemic nature for the Human Right

- Do you qualify for CLDS (Community Living Disability Services) YES / NO
- Are you involved with an organized day program? YES / NO If YES, please provide the name of the program and the extent to which you attend on a weekly basis. _____

If NO, how do you occupy your time throughout the day?

- Do you still live with your parents / guardian? YES / NO
- If Yes Do you require a caregiver? YES / NO If YES, who is your main caregiver and what are your personal needs?

If NO, where do you live, and who looks after your needs? (Example: Supported

· What (Hom · Is you · Do yo	necare)Hours; \$ or home care self-administered? YES/NO ou wish to provide additional	
	 Does this include rent? YES/NO What do you receive for biweekly care? (Homecare) Hours; Is your home care self-administered? YES/NO Do you wish to provide additional information / comments that may be helpful 	
• Do you deal with depression? How are you presently dealing with it? • What do you receive in EIA monthly?		
_	• Do you face loneliness and isolation in you life? YES / NO Additional comments:	
with a	a group of people (able-bodied and led)? Please explain your reasons.	
paren	If you are already living away from your parents' home, would you be interested in moving into a communal home environments.	
	bodied and disabled), or in a private sible home? Please explain your reasons	
If YES	s, would you prefer to live in a communa e environment with a group of people	
-	ı live at home, would you like the rtunity to move out? YES /NO	

THANK YOU!