



PAVE THE WAY

vision to action through planning

A Place to Call Home

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Thinking it
Through

2013

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Introduction

Thinking about the future for our relatives with a disability can be a complex and sometimes difficult process to engage in. If we acknowledge, however, that the future really does begin today rather than at some distant time in the future, then we need to start planning now for the best possible life we can imagine for our family member.

Where they will live is one of the big questions to which there is no quick or easy answer. A common community response to the question of where a person with a disability might live is to find, or lobby the government to provide, a group home where people with disability live together with paid support workers. This, however, is not the only possibility.

People with disability live in all sorts of different living arrangements in the community: in private rental accommodation; in public housing properties; in houses they own or that are owned for them in trust; in independent apartments attached to family properties.

Living independently does not necessarily mean living alone. An important consideration is that there is an element of choice in where a person lives. Although some people may choose to live alone, others may choose to live with someone else – a friend or a flat mate - who may or may not have a disability.

'When people with a disability can take control of their own housing and their own lives, just like everybody else, they create better solutions'. (Dyke, 2007, p.3)

Sometimes people may think that a person's support needs are too high for them ever to be able to live in a home of their own. However, many people with disability have proven that even with quite complex needs, they have been able to live independently if they have the right people in their lives to support them through both formal and informal arrangements.

David ...lives with many physical and developmental disabilities... – he cannot walk; he cannot talk. ...people who didn't know David well enough, thought he could never live alone. Today,David does live alone and in a place of his own. Not possible? Well, David has achieved the impossible all his life. (Ouellette, 2008, p. 9 - 10)

What is a home?

'To most of us our home is our sanctuary where we have a sense of ownership, privacy, retreat, security and belonging' (Community Safeguards Coalition, 2009, p.1)

The concept of home as being fundamental to a person having a good life is universally accepted. Therefore, the important thing for anyone is that their home is truly a home, that is, a place where they can:

- express their own identity, story, interests and passions
- show hospitality, develop real relationships and experience intimacy
- feel safe, and can rest and renew

One mother, whose daughter has moved into a home of her own, describes her daughter's strong sense of what her home should be like:

Jessica had to have a pink couch – she was not going to live there unless there was a pink couch. She chose lots of pink and fairies and butterflies. Jessica and her support worker have made some lovely art works with beads and some paintings and they are hanging on the walls of her house. She has had a couple of good parties here and enjoys inviting people over. Jessica loves her home - she is quite bossy about how she wants it decorated and what she wants everyone to do. She does not like to go to our house and will often sit in the car until she can go home again. I think Jessica would be broken hearted if she had to leave her home.

For people with disability who live in places not of their own choosing with people they do not know, there is often little or no sense of this aspect of home. For many it can be a case of being 'housed but homeless'. (Kendrick, 2009)

A home is 'a place of your own in the community where you are seen to belong'.
(Community Safeguards Coalition Campaign, 2007, p.15.)

Equally important to having a sense of identity and ownership is the experience of belonging to the community in which you live.

Why should this be any different for people with disability?

Peter... participates in his local community. He is known by his neighbours, which we believe is a valuable safeguard. He has three young men supporting him and it is pleasing to see the fondness and respect between Peter and his staff. We often rely on Peter's body language for clues about his inner feelings, so observing Peter when he returns home to his unit, leaves no doubt that he is happy. (Listopad, 2009, p. 2.)

One parent talks about the changes that came about for her daughter after she moved out of a group home and into her own unit near her family:

Today Julia's life is radically different. Living in the community has enabled Julia to make her own life choices. She is more independent, has real friends and freedom that would never have been possible in her earlier life. Living in the community has also enabled Julia to gain greater skills and knowledge and as a result, her reliance on support has diminished. She makes her own decisions about most things, especially about which staff are appointed to support her.

Julia enjoys doing her own cleaning and laundry, going shopping and managing her own bank account and with help, has been managing very well. Although she loves spending time in her unit, on weekends she is rarely at home.she has made a number of friends with whom she sometimes gets together for coffee, movies or dinner ... fun things that were impossible in the past. (Listopad, 2009, p.1 – 2)

"It is important to realize that moving people into houses in the community does not necessarily ensure enhanced quality of life." (Queensland Disability Housing Coalition, 2002, p.11)

Thought and care also needs to be invested in the social and emotional aspects of a person's life because 'the central lifestyle question is not where people live but what people do each day.' (Kendrick, 2009)

An integral part of this will involve building relationships in the person's life because a person could be living in their own place within the community and still be isolated unless they have networks of personal support.

It is therefore essential that planning for a good life comes before planning the place where someone will live. i.e. you need to start with the person first rather than with the bricks and mortar. As Wendy Stroeve writes, '...once you have created a vision of a positive life and begun to articulate it to others, you also have created a kind of compass for navigating your way to that outcome.' (Stroeve, 2007, p. 4)

Of course, this kind of planning and 'navigating' can start well before a person is of an age to live independently.

Donna and Ben know what sort of life they want their 23 year old son, Jonathon, to live so they are now working towards making their vision a reality. They have gathered a network of people around him and have got him involved in local community events and activities which include him becoming a member of his local gym. If the family eats out with Jonathon, they do so in the local cafes and coffee shops and they have asked his support workers to do the same. They have organized for Jonathon to start a small delivery service around his local area so that he is meeting his customers on a regular basis and he is also doing some volunteer work in the area. His parents are also working towards him developing more independent living skills whilst he is still living with them in the family home. Their plan is that by the time Jonathon is ready to move into a home of his own, he will have developed a full and interesting life and be well known in his local community.

Planning for a home then, is more than just finding a place to live. Rather it is planning for a person to live a fulfilling and meaningful life in their own home within the community

The following ideas may be helpful as you begin to think through how this might happen. The following list of questions may help by providing a starting point for your thinking and investigations. It is not intended to be an exhaustive list of questions, or the only ideas to consider, but may provide some focus for your planning.

The starting point

- What sort of life does your family member want to live? What is their vision for their life?
- What sort of life would you like them to lead now and in the future? What is your vision for their life?
- What sort of living arrangement would best enable them to live this life?

When is the right time?

- Do you want to put something in place that you and your family member have control over rather than waiting until an emergency situation or a crisis occurs over which you have no control?
- Has your son/daughter indicated that he/she would like to live independently?

Even if the person with the disability cannot clearly articulate their thoughts and desires, it does not mean that they don't wish for the same things as everyone else. However, it often involves a deep understanding of the person to be able to pick up on what they really want. As Alison Ouellette (2008, p. 48-49) says,

The subtle gestures, emotions and body language Dave exhibited were cues. I could have ignored those cues; I could have pretended they were not really communication. But, the signs meant that Dave was ready. It took until he was settled in his new place to feel confident, assured and happy that we had listened to and interpreted his wishes correctly.I know that listening is the place to start.
(Ouellette, 2008, p. 48 - 49)

- Does your son/daughter have the resources required for them to live independently?
- Are you ready to let go? (Sometimes we hold our children back through our own fears)
- If you wait for all the right elements to be exactly in place, it may be that the right time will never come. Sometimes, it is simply a matter of taking that first step.

One parent explains how, although she did not feel ready, she decided to take up the opportunity when it was presented for her daughter:

I got the call just before Christmas. "There is a house available for Jessica if she wants it, but it is ready now" – I was shocked speechless.

We had been meeting with our Support Circle for about 5 years and talking and planning for Jessica to live in her own house.....but we weren't ready. I hastily rang some women I know who have worked with other families going through this same process. As one of them said, "Well, she can always come home if she doesn't like it".

So, Jessica and I went to look at the house. It was perfect – it was everything we wanted for her. We started out slowly with Jessica staying at her house 2 nights a week with me and then back to our house for 2 nights. She was staying at her house full time in about a month. It was a much quicker transition than we had expected.

What will it look like?

- What type of housing?
- Where would they live?
- Who would they live with?
- How could it happen?
- Can the living arrangement be sustained in the long term?
- Can a 'typical' lifestyle be maintained?

What will it take for your family member to live independently?

- What sort of support does your family member require in his/her daily life?
- Has your family member developed independent living skills whilst living in the family home?
- Is there a way of further fostering the development of these skills? Are you currently doing things for your son/daughter that they are capable of doing for themselves?
- Are you willing for your son/daughter to take some risks within a supportive environment?
- Have you developed any informal networks around your family and son/daughter?
- Is your son/daughter well known and respected within their local community so that others would look out for them if they were living independently in the community?
- Are there other families who are looking for similar options who you could work with?

It is a good idea to remain connected to other families to share experiences and challenges, to support each other and to swap ideas/information about strategies, services and supports.

What support/resources will be needed?

- Daily personal care
- Overnight support
- Help with household chores – e.g. cooking, cleaning, gardening
- Moral support/companionship
- Support with activities in the community – e.g. shopping, employment, leisure/social activities
- Support with financial affairs – banking, payment of bills, taxation
- Transportation

How will support/resources be provided?

The reality is that very few people with disability are currently being given individual funding packages where the funding follows the person. Rather than waiting for funding to fall into your lap, be proactive! Think creatively about some different options and try to think outside the square, especially as to how support could best be organized without being fully financially dependent on

government funding which may bring with it decreased choices. Ouellette (2008, p.51) suggests, 'If you feel that you don't have enough funding support, don't stop from making the decision for independence; look at alternative live-in support arrangements.'

- What benefits/funding opportunities are available?
- Do you have a long-term investment strategy in place which will reduce your family member's dependence on public funding?

If you do have funding, consider the following:

- How can the funding be best used? (Is it being used to improve your family member's life?)
- Is the funding sustainable in the long term?
- Will the funding respond to changing needs?
- Can the funding be taken to another housing arrangement if necessary?
- Will my family member only receive the funding if they share with another person with a disability? (forced co-tenancy)
- Is the financial support separate from the housing? (Having housing and support as separate arrangements is a major safeguard especially when someone has complex needs)

Types of support

Some families use a combination of paid and unpaid support. Some examples are:

- Sharing with flat mate/s without disability – full rental at market rate or minimal or no rent in exchange for support/companionship
- Choosing to share with another person with disability that your son/daughter is friends with and sharing support
- Visiting support workers – support during the day, overnight support (this may involve a number of different workers)
- Live in support worker/s
- Support from someone who could apply for a Centrelink Carer Payment
- Informal support - e.g. family, friends, neighbours, support circle, local community members

Issues to consider around support:

- How will the support be organized? (through an agency?, private advertisements?, through informal networks?)
- How would you organize interviews and what questions would you ask?
- Is the support reliable, responsive and flexible?
- How will you ensure that the continuity of support is sustainable in the long term?
- Who will coordinate this in an ongoing way?
- What are the belief systems of the support workers about disability?
- Do the support workers mirror what you expect from others in the community?

Other considerations:

- How can your family member have authority over their own lifestyle and support arrangements? (e.g. Is the ownership/tenancy held by your family member, which gives security of tenure?)
- How can you ensure that it really feels like your family member's home rather than as the workplace of paid workers? (i.e. Are support workers/tenants tending to "take over" the home or acting as visitors?)
- Are 'typical' household routines being observed?
- How can you assist your family member from not being isolated?
- What safeguards against risk of abuse or neglect can you put in place?

Sharing with others can be a very successful model for many people, as living alone does not suit everyone. However, it is very important to consider what choice the person has in who they share with because 'living with the "right" others is important'. (Kendrick, 2009)

Sharing with a person without disability

This may be a very workable option for many people with disability. Contrary to some people's assumption that no one would want to live with someone with disability, this is an arrangement that has in fact met with a great deal of success. People have found that unpaid housemates have often developed long lasting relationships with the person, which have continued, after the house sharing arrangement has ended. Sharing a home involves a reciprocal relationship and it is important to realize that everyone, including those with disabilities, has their own special qualities that connect them with other people.

However, if considering such a share arrangement, it important to be aware of whose home it will be and whose identity the home will reflect. There is a potential conflict between a housemate being more likely to stay if they feel a strong sense of home and it being at the cost of the person with disability who may find it more difficult to forge this sense of ownership and identity.

For some people with disability, it could be that simply having someone sleep over to ensure their well-being, ends up being a better solution.

Some supports that a flat mate without disability may provide:

- Cooking /sharing meals
- Shopping for groceries and household items
- Household tasks (cleaning, laundry, yard maintenance)
- Personal care requirements (may include administering medication)
- Helping with financial tasks – paying rent, bills
- Companionship at home or for outings
- Connecting the person with their community
- Helping the person to develop relationships with others

If using this approach, you would need to work out an agreement or contract which would include the financial arrangement, how many hours of support a week would be provided, what type of support would be required and how the home is to be used.

One example of how this might work is that housemates could have an ordinary lease agreement with an added page of special conditions as to what their role would be in relation to the person with disability. The cost of rent could then be negotiated depending on how much time the housemate will spend in this role. Families have found other individual arrangements that have also worked well for them.

To keep the housemate contract as informal as possible, we made a verbal arrangement with (the worker) for a one-year commitment. In exchange for overnight care and support....the arrangement included free rent, utilities, household supplies and furnishings that included a computer. (Ouellette, p.32)

Jessica has had three housemates who have lived with her and “kept an eye on her” overnight for some nights - in return for low rent or no rent. We make up a rental agreement and discuss it with the person when they are applying to share Jessica’s home.

For some people, the best solution may be to organize a typical housemate arrangement where the housemate pays normal rent with no expectation of support. You would anticipate that in this situation, a typical housemate relationship would naturally form.

Sharing a home with someone with or without disability

In any shared living arrangement, it is essential that you know your rights.(e.g. Who will sign the lease? How will bond requirements be shared?) Regularly review and update all information regarding the rules around tenancy agreements. (<http://www.rta.qld.gov.au>)

The following, are examples of some of the issues that you may want to discuss/consider as a starting point in finding the right person to share accommodation:

Compatibility

- Age
- Gender
- Communication – can people understand each other?
- Support needs/security needs
- Cultural/social customs
- Interests/lifestyle differences/leisure activities
- How much time will each person be spending in the house?
- Smoking/ drinking

Financial considerations

- Ability to contribute to setting up the household (e.g. furniture, kitchen utensils, white goods)
- What household items are to be shared
- How each person contributes to household expenses (food, utilities, phone)

Task sharing

- How to organize preparing, cooking & sharing meals
- Sharing of housework
- Who will take care of maintenance

How the home will be used

- Car parking needs
- How many friends/family will want to be spending time in the home
- Overnight guests
- Parties/social gatherings
- Noise issues (TV use, musical instrument, playing radio/music)
- Companionship versus privacy needs

Co-tenancy /Group Homes

It is very important to be clear about "chosen co-tenancy" versus "forced co-tenancy".

If you intend to rely solely on government funding, you need to be aware that 'Congregated care.... is emerging as the dominant model for accommodation and support for people with a disability.' (Dyke, 2007, p.4)

The government often enforces a model of co-tenancy as a response to a request for funding without providing any real choice. Because of inadequate support packages, people are often placed in shared housing arrangements with other people with disability using a system of "vacancy management".

However, if it becomes simply a matter of placing someone where there happens to be a vacant bed, there is likely to be little consideration of the person's individual needs and what constitutes a real home for someone. It is important to realize that 'A bed in a house is NOT a home.' (QPPD, 1992)

Also because life in these group homes is often organized around the stereotyped needs of the group, '...clustered accommodation facilities are more likely to be counter-productive in addressing behavioural issues' (Carter 2006, p.13 -14)

At Peter's residential home, conflict among the residents and the constant staff changes had a detrimental effect. His behaviour changed and staff informed us that they could not manage him. (Listopad 2009, p.1)

(This is the same young man, mentioned previously in this article, who is now living happily in his own home and has a good relationship with his staff.)

'For shared housing to have any possibility of providing a positive response for people with a disability, they and their family/advocates need to be included in the decision making process.' (Queensland Disability Housing Coalition, p.5)

So, if you do decide to embark on this option of congregated living for your family member with disability, you would need to carefully consider what sort of lifestyle they would be able to achieve in this arrangement and ask yourselves some important questions such as:

- Is it possible to maintain my vision for my family member in this type of living arrangement?
- Do the values and beliefs of the service organization fit with my belief system about disability?
- How easily can my family member or I change the housing arrangement if it does not suit? (If the viability of the household is dependent on co-tenancy, it can be extremely difficult for a person to move if they wish.)
- Is the home located so that my family member is still living in their local community?
- Can my family member's current lifestyle be maintained? (work, education, recreation, social, spiritual)
- Does my family member have any choice in who they live with?
- How many people are living together? Are these people compatible? Do they have common interests/abilities?
- Can my family member or can I be involved in any of the decision making within the household?
- Do I (or my family member) have any choice in the employment of support workers?
- What are the belief systems of the support workers in the home?
- How rigid are the daily routines?
- Are my family member's individual needs/desires being met?
- How well does the service adapt to the changing needs of my family member?
- Does it feel like a home (a pleasant place in which to live) or a mini-institution?
 - Is there any private space?
 - Can I visit whenever I want to?
 - Can a number of people visit my family member at the same time?
- What safeguards can be put in place to ensure there is no risk of abuse or neglect?

Is the housing suitable?

If you decide to rent or purchase a place for your family member, there is a lot to think about to ensure that the housing is suitable for their needs.

The following list outlines some factors that may help you in your decision making.

- What type of home?
 - Detached house
 - Semi-detached house
 - Unit
 - Flat

- Townhouse
 - Duplex
 - Separate housing attached in some way to the family home. (e.g. granny flat, next door apartment)
- Location
 - Proximity to amenities – shops, transport, services?
 - If relevant, are these amenities wheelchair accessible?
 - Is it situated in the community where they want to live?
 - Proximity to daily activities?
 - Proximity to family, friends, allies?
 - Are there neighbours nearby? Are they likely to be of similar age?
 - Does it ensure the maintenance of their current lifestyle?
- Size & space
 - How many bedrooms?
 - How many bathrooms? – are they accessible? Do they need a bath?
 - Are the living spaces large enough to accommodate a number of people?
- Tenancy – what length of tenure is available? Is this likely to be renewed?
- Affordability – initial, ongoing
 - What percentage of the person's pension will be required for rent/mortgage?
 - Are there body corp/administration/sinking fund fees?
 - What are the rates/cost of insurance/cost of utilities?
 - Is it affordable in the long term?
- Is it well designed?
 - How adaptable is the housing to different living arrangements which include formal and informal supports? (i.e. number of bedrooms and bathrooms)
 - Will it allow for a diverse range of households to occupy the residence cost effectively and equitably over time?
 - How easy will it be to change living arrangements in the future as circumstances change?
 - Is there enough room for shared and private space?
 - Are there outdoor living areas – yard, balcony, courtyard, deck
 - Laundry - is this easily accessible to the living areas? Does it have its own clothes line?
- Is it accessible
 - Is it suitable for specific needs? If not, can it easily be adapted?
- Repairs and Maintenance? (house and yard)
 - Age of the housing – will there be a lot of ongoing maintenance?
 - Who will look after the ongoing maintenance now and into the future?
- Has the housing got broad market appeal?
 - Would other people want to live there?
 - Would it be easy to rent/sell if you wish to change the situation?
- Is it safe and secure? (person, tenancy, possessions, area)
- Is it in a socially valued area? (SRV test)

Conclusion

'The final outcome should be a home environment similar to the one your son or daughter has been accustomed to. Your son or daughter will want to live in a community where they feel welcome; where they can participate and enjoy friendships, neighbourhood activities, and one that has a community spirit that enlivens everyday life. Your son or daughter will need to have a place where they are in charge. Everyone wants their private domain to be their personal kingdom.' (Ouellette, 2008, p.52-53)

'Keep positive and remember – anything is possible.' (Ouellette, 2008, p. 53)

'Rather than saying "it's not possible", we need to pen our hearts and minds to the liberating idea that anything may be possible if we put our minds to it and if we imagine better...' (Rouget, 2003, p. 4)

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(All of the stories used in this article are the stories of real families. In some cases, however, names have been changed.)

Suggestions for further reading

Websites

<http://gettingalife.com.au/> (As seen in the workshop)

Website from The Getting a Life Intentional Community is a 25-residence housing and community building project that is structured around the lives of Daniel, Ben and Jackson. Three houses are set aside, one for each of Daniel, Ben and Jackson. The remaining 22 units will be allocated to existing Housing ACT tenants who apply.

<http://www.supportedliving.org.au>

Website from New South Wales dedicated to information about supported living for people with disabilities. Resources, articles and stories of how people with disabilities and their families have organised the support they need to live in their own homes.

<http://www.homeswest.org.au/>

Website from Homes West, a small community based service in Brisbane which supports individuals to establish and to live in homes of their own and to be included as active and valued members in their local community. Includes articles about the history of the organisation and how it works.

<http://www.clp-sa.org.au/>

Website for Community Living Project, South Australia, which works to enable people who have disabilities to achieve a purposeful and valued community life. Includes news stories about people they have worked with.

<http://www.communityworks.info/index.htm>

Website of David and Faye Weatherow, Community Works, Canada. Includes a range of articles around what it takes for a person with a disability to live a good life in the community.

<http://www.plan.ca>

Website of Planned Lifestyle Advocacy Network in Ontario, Canada. This website includes a number of resources that would be useful as, even though it is intended for families within Canada, the themes are universal.

Books/Articles

A Home of My Own - Right, Rhetoric or Reality?, Queensland Disability Housing Coalition Inc (2005)

The QDHC was an independent community based organization that acted as a peak body to represent the housing needs and associated interests of people with disabilities in Queensland. This resource written by Jan Dyke outlines many of the issues to consider around housing and creating a sustainable future for people with disabilities.

My Life, My Home, My Solution, Community Safeguards Coalition Campaign (2007) Updated 2009 version also available.

The Community Safeguards Coalition is a network of people including people with disabilities, families, friends, advocates and allies of people with disabilities who are committed to safeguarding the human rights of people with disabilities in Queensland. This booklet tells the stories of a number of vulnerable people and how their housing options have affected their lives.

(<http://www.qppd.org/downloads/MyLife,%20My%20Home,%20My%20Solution.pdf>)

Creating Housing Choices for People with Developmental Disabilities in Ontario, Itay Greenspan & Loral Raine (2006)

Looking Forward to Community Living: My own life, my own home, in communities where we all belong

A booklet from the Western Australia Disability Services Commission that outlines various models of community living for people with disabilities <http://www.housing.wa.gov.au/housingoptions/Pages/default.aspx>

Home is where the Heart is A booklet for families in British Columbia, Canada who are looking for accommodation options. It discusses the issues to consider, various housing options developed by families and discusses the advantages and disadvantages of home ownership. (www.plan.ca)

**The Homes West Experience*, compiled by Jill Hole (2007)

The story of Homes West, a small community based service in Brisbane, which supports individuals to establish and to live in homes of their own and to be included as active and valued members in their local community. Includes articles about the history of the organisation and how it works.

**A Place Called Home*, Alison C. Ouellette (2002)

The story of how a Canadian family achieved what they first thought was impossible – that their son, who was born with profound physical and intellectual disabilities, would live in his own home, hire his own assistants and run a small business. His mother tells the story of this journey.

**We Come Bearing Gifts*, Janet Klees, (1996)

The story of a small group of ten Canadian families who formed the Deohaeko Support Network in order to achieve their vision of a positive future for their sons and daughters who have a disability. They gained funding to build the Rougemount Co-operative – a 105 unit housing apartment where their sons and daughters now live independently. This book tells the individual stories of this journey.

**Our Presence Has Roots*, Janet Klees (2005)

The ongoing story of the Deohaeko Support Network – “an ongoing story about community, about change, and about a group of families in Pickering, Ontario who are determined to make their community a changed and better place for all”

***The importance of starting with the person rather than the money* Deb Rouget: Crucial Times (27 July, 2003)

Deb Rouget writes about the fact that “some things ... money cannot purchase and produce” and that for someone with disability to live a typical life, it is important for them to build relationships and to seek opportunities to become actively involved in their local communities.

***Clarity of Vision: A Compass for the Journey*, Wendy Stroeve (2007)

Wendy Stroeve, a mother and a teacher writes about the importance of having a vision, that is, a clear idea and some positive dreams about the kind of life a person with disability wants to achieve. She suggests that this vision of a positive life can become a kind of compass, a tool to assist a person with disability and their family navigate toward a rich and varied life within their community.

***Home: A Place Of My Own Where I Belong*, Anita O’Brien (2007)

Anita O’Brien, a Melbourne mother of two sons writes about the journey her family has taken to ensure that her son, Warren, leads the life of a typical 30 year old – “one that saw him on the natural pathways of life, in valued roles that make sense for him.” Since this article was published, opportunities for Warren to participate within his community have continued to arise out of the decisions that the family has made.

*Book can be borrowed from the Pave the Way library **Article can be found on the Pave the Way website