



# A Literature Review to Inform the Development of a National Framework for Person-Centred Planning in Disability Services



**New  
Directions**

Building a  
Better Health  
Service

Seirbhís Sláinte  
Níos Fearr  
á Forbairt



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This report was commissioned by the National Disability Authority and the HSE on behalf of the National New Directions Implementation Group.

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## Terminology

A number of terms are used to describe people in the literature reviewed in this research report. These include terms such as people with disabilities, people with intellectual disabilities, caregivers, and service users. This report uses the same terms that were used in the literature that is being referred to.



## I. Executive summary

This literature review on person centred planning (PCP) was commissioned by the Health Service Executive and the National Disability Authority (NDA) to inform the development of a national framework on PCP across services provided to adults with disabilities in Ireland. A set of guidelines were developed by the NDA in 2005 on the principles and implementation of PCP.<sup>1</sup> This literature review examines evidence on the implementation and effectiveness of PCP in the international literature, from 2005 to 2016, to inform the framework.

Although there is no consensus on the definition of PCP in the international literature, the NDA defines PCP as a “way of discovering how a person wants to live their life and what is required to make that possible. The overall aim of PCP is good planning leading to positive changes in people’s lives and services” (p. 12).<sup>2</sup>

The literature review was conducted around three areas:

- Evidence available on the use of the key elements identified in the 2005 guidelines
- Evidence available on the effectiveness and implementation of PCP with a particular focus on transitions, social inclusion, independence and risk taking
- Evidence on models of best PCP practice for an exploration of employment.

The methodology employed to conduct the literature review consisted of thorough searches of seven electronic databases: Web of Science, Psychinfo, Cinhal, Pubmed, Embase, Eric and Proquest Dissertations. The search was filtered by years (2005-2016), full-text articles, published books and peer-reviewed journals in English. Manual searches of journals, bibliography lists, and searches in Google and Google Scholar completed the search. The work was conducted with support from a panel of expert members.

Before presenting a summary of the literature review, clarification on the differences between PCP and other forms of planning, with which PCP is commonly mistaken, is outlined:

- Person-centred active support: everyday person-centred micro-planning of activities and support<sup>3</sup>
- Care management: planning for the provision of services based on an assessment of need and linked to resources<sup>4</sup>
- Individual support planning and individual person planning: planning that focuses on the needs of people as assessed by inter-disciplinary teams<sup>5</sup>

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<sup>1</sup> (National Disability Authority, 2005)

<sup>2</sup> (National Disability Authority, 2005)

<sup>3</sup> (Jones & Lowe, 2008)

<sup>4</sup> (Cambridge, 2008)

<sup>5</sup> (Taylor & Taylor, 2013)



- Individual education planning: planning that occurs during and focuses on the needs and supports at school and the transition out of school<sup>6</sup>
- Personalisation: service provision that focuses on the self-determination of the person with disability to shape services and support.<sup>7</sup>

### **1.1. Evidence available on the use of key elements identified in the 2005 NDA guidelines**

The literature review conducted suggests that the four elements of PCP presented in the 2005 guidelines are still valid (see Table 1.1). We next highlight relevant aspects to the implementation of PCP which are identified through the literature review.

**Table 1.1. Key elements of good practice**

1	Establishing a framework
2	Clarifying roles and responsibilities and identifying any training and support that will be required
3	Identifying plan-facilitators and ensuring that they are adequately trained, experienced and supported
4	Establishing mechanisms of ongoing communication, plan management and the monitoring, evaluation, review and development of the PCP process

Source: Guidelines on Person Centred Planning in the Provision of Services for People with Disabilities in Ireland<sup>8</sup>

#### **1.1.1. Establishing a framework for PCP**

There are some new elements highlighted in the literature from 2005 as part of developing the PCP framework:

- Training for the person
- Self-advocacy
- Involvement of people with disabilities in quality assurance of services.

There is evidence in the literature reviewed that PCP training, preparation, skills building, and implementation have resulted in an enhanced sense of autonomy and self-determination in participants with intellectual disabilities.<sup>9</sup> These results suggest that training can contribute to developing a positive view of the person, their current situation and their future ability to engage in planning.

Another finding of the literature review is in relation to advocacy. There are five dimensions to advocacy:

<sup>6</sup> (Meadan, Shelden, & DeGrazia, 2010)

<sup>7</sup> (Genio, 2012)

<sup>8</sup> (National Disability Authority, 2005)

<sup>9</sup> (Wehmeyer, Garner, Yeager, Lawrence, & Davis, 2006)



- PCP should be approached as a form of self-advocacy where the person can advocate for their life goals<sup>10</sup>
- Advocacy training for people with intellectual disabilities has been identified as critical in enabling people to articulate the lives they want to have as part of the PCP process<sup>11</sup>
- Advocacy by service provider organisations at the systems level is necessary to enhance the opportunities for people with intellectual disabilities to live in the community, work, study, have relationships, etc.<sup>12</sup>
- People with intellectual disabilities should join self-advocacy groups beyond their organisations<sup>13</sup>
- The advocacy function of people with intellectual disabilities can be extended to auditing and inspection of services<sup>14</sup>
- Independent advocates can support people with intellectual disabilities to participate in planning and this is more critical when people have communication difficulties.<sup>15</sup>

A person-centred service culture should have the core values of inclusion and self-determination and aim to give power to service users.<sup>16</sup> For people and families to hold power over their lives, organisations need to accept and act upon the decisions that people with disabilities and their families make.<sup>17</sup> To make the voices of people and their families stronger, the literature recommends conducting planning through informal environments and informal relationships between staff and persons with disabilities, where staff recognise the natural authority of the person and the family regarding the person's life.<sup>18</sup> This is accomplished through listening and 'giving credence' to what the person with disability says and responding to their needs (p. 17).<sup>19</sup> Finally, decision making procedures should be reviewed to ensure a person's PCP is not in reaction to an immediate crisis situation or about easy decisions.<sup>20</sup>

The development of a person-centred culture has been identified as one of the main challenges to effectively implementing PCP.<sup>21</sup> It has been recommended that PCP is incorporated at all levels of an organisation and it becomes integral to the

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<sup>10</sup> (Cambridge & Carnaby, 2005; Walker, 2012; Wehmeyer et al., 2006)

<sup>11</sup> (Cambridge & Carnaby, 2005; García Iriarte, 2009; Walker, 2012)

<sup>12</sup> (Robertson & Emerson, 2007; Walker, 2012)

<sup>13</sup> (Cambridge & Carnaby, 2005; Walker, 2012)

<sup>14</sup> (Cambridge & Carnaby, 2005; Mazzotti, Kelley, & Coco, 2015; Walker, 2012)

<sup>15</sup> (Parsons, Cocks, & Williamson, 2009)

<sup>16</sup> (Dowling, Manthorpe, & Cowley, 2007)

<sup>17</sup> (García Iriarte, In press)

<sup>18</sup> (Cocks & Boaden, 2011)

<sup>19</sup> (Parsons et al., 2009)

<sup>20</sup> (Bigby, Fyffe, & Ozanne, 2007)

<sup>21</sup> (Dowling et al., 2007; Ratti et al., 2016)





organisation.<sup>22</sup> Organisations require flexibility to collaborate with other service providers and apply community-building approaches to planning.<sup>23</sup> Staff capacity building has been identified as a key enabler of a person-centred culture, for example through:<sup>24</sup>

- Training
- Decentralisation of resources and responsibilities
- Horizontal management
- Accessible communication
- Advocacy.

A recent project aimed at changing the organisational culture towards the individualisation of services have employed PCP along with training, organisational strategic planning, and connections with the community and the State to shift the organisation towards an individualised support culture.<sup>25</sup>

### **1.1.2. Clarifying roles and responsibilities**

The relevance of roles and responsibilities identified in the 2005 NDA guidelines has been confirmed through the literature. A mix of support, formal and natural, has been found to help people accomplish their desired outcomes.<sup>26</sup> Plans should have a clear implementation strategy and assigned responsibility for implementing the strategy, as a lack of responsibility leads to unmet goals.<sup>27</sup>

#### **1.1.2.1. The person who is the focus of the PCP**

It should be imperative for the person who is the focus of the PCP to have a central role and to be involved in planning.<sup>28</sup> The person needs to communicate their needs, wishes, and preferences, make decisions about the planning process, the plan, and make informed choices about support for the meetings and to implement and evaluate the plan.<sup>29</sup> Individualised supports and accommodations should be provided as needed, for example communication devices or opportunities for breaks during the meeting.<sup>30</sup> An independent advocate for people with communication difficulties has been also recommended.<sup>31</sup> Certain elements have been identified as necessary

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<sup>22</sup> (Cambridge & Carnaby, 2005; Dowling et al., 2007; Fitzsimons, 2012; Parsons et al., 2009; Robertson et al., 2007; Taylor & Taylor, 2013; Walker, 2012)

<sup>23</sup> (Cambridge & Carnaby, 2005; Dowling et al., 2007; Fitzsimons, 2012; Parsons et al., 2009; Robertson et al., 2007; Taylor & Taylor, 2013; Walker, 2012)

<sup>24</sup> (Cambridge, 2008)

<sup>25</sup> (Walker, 2012)

<sup>26</sup> (McConkey & Collins, 2010)

<sup>27</sup> (Robertson & Emerson, 2007)

<sup>28</sup> (Cambridge & Carnaby, 2005)

<sup>29</sup> (Bigby et al., 2007; Cambridge, 2008; Parsons et al., 2009)

<sup>30</sup> (Beckwith, Friedman, & Conroy, 2016b; Towers & Wilkinson, 2014)

<sup>31</sup> (Parsons et al., 2009)



for people with intellectual disability to take a leadership role in organisations, which could be adapted to their leading role in PCP:

- Authentic membership
- Deliberate communication
- Full participation
- Meaningful contributions
- True influence.<sup>32</sup>

#### 1.1.2.2. Staff implementing PCP

Staff have been identified as one of the most powerful enablers of goal implementation and accomplishment.<sup>33</sup> For staff to implement PCP more effectively, research has reported that programmes of activities and information have to be written and accessible, staff should be working jointly with open communication about the plan and they should be directly involved in planning.<sup>34</sup> Implementing PCP does not mean that new staff have to be hired – staff can be re-trained to facilitate the continuation of relationships between staff and persons with disabilities.<sup>35</sup> However, staff's attitudes about service users' potential to be independent need to be reviewed.<sup>36</sup> Good support from the point of view of people with intellectual disabilities involves: respect, facilitation of choices, friendliness, and giving advice and support to speak up.<sup>37</sup> Strategies used by good support staff include: stepping back, talking in an adult tone of voice and following the lead of the person with intellectual disabilities.<sup>38</sup>

#### 1.1.2.3. PCP facilitators

PCP depends on the availability of facilitators committed to PCP.<sup>39</sup> Facilitators who are in management roles are more likely to deliver plans and the person who is the focus of the plan is more likely to benefit from them.<sup>40</sup> The literature recommends that PCP facilitators are independent from the organisation<sup>41</sup> but this is hard to achieve in practice.<sup>42</sup> Facilitators should develop relationships with the person who is the focus of the PCP and be available throughout the process (before, during planning and at follow up).<sup>43</sup> It has also been recommended that different people take

<sup>32</sup> (Beckwith, Friedman, & Conroy, 2016a)

<sup>33</sup> (Claes, Van Hove, Vandeveld, van Loon, & Schalock, 2012; Fitzsimons, 2012; García Iriarte, 2009; McCarron et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006)

<sup>34</sup> (Windley & Chapman, 2010)

<sup>35</sup> (García Iriarte, Stockdale, McConkey, & Keogh, 2016; Robertson et al., 2006; Walker, 2012; Windley & Chapman, 2010)

<sup>36</sup> (McCarron et al., 2013)

<sup>37</sup> (Inclusive Research Network, 2015)

<sup>38</sup> (Williams, Ponting, Ford, & Rudge, 2010)

<sup>39</sup> (Parsons et al., 2009)

<sup>40</sup> (Robertson et al., 2006)

<sup>41</sup> (Cambridge, 2008; Chengqiu Xie, Hughes, Challis, Stewart, & CambridgeO, 2008)

<sup>42</sup> (Chengqiu Xie et al., 2008)

<sup>43</sup> (Hagner et al., 2012; Hagner, May, Kurtz, & Cloutier, 2014; Wehmeyer et al., 2006)



the roles of facilitator and support staff that implement plans.<sup>44</sup> Only people who have experience in PCP should be responsible for it.<sup>45</sup>

#### **1.1.2.4. Natural support**

A common characteristic of PCP is the involvement of a network of informal support, to complement services but not to replace them.<sup>46</sup> Although the family has a central role in supporting the person,<sup>47</sup> there is a documented risk for families to become over-involved and mis-represent their relatives' preferences if they speak for them.<sup>48</sup> Siblings' support needs should also be considered.<sup>49</sup> A common approach to develop informal support is through circles of support, involving family members and advocates.<sup>50</sup> When people with intellectual disabilities have a small network of contacts, this should be addressed early in the planning process.<sup>51</sup>

### **1.1.3. Identifying training and support that will be required**

Training has been identified as a core component of PCP implementation. The value base of PCP should be the focus of training for all staff working in the organisation including managers. The following training areas have been recommended for PCP stakeholders.

#### **1.1.3.1. The person who is the focus of PCP**

- Training on self-advocacy, making decisions, strategies for funding services such as individualised funding, communication skills, building social capital, human rights, goal setting and choice making.

#### **1.1.3.2. Staff implementing PCP**

- Training on PCP implementation, human rights, communication skills and person-centred active support.

#### **1.1.3.3. PCP facilitators**

- Training on PCP context and values, PCP facilitation and implementation strategies such as communication with an emphasis on listening and community inclusion.

#### **1.1.3.4. Natural support**

- Families should be trained on individualised supports, self-advocacy, legal and financial strategies, PCP and decision making.<sup>52</sup>

### **1.1.4. Establishing mechanisms for communication, monitoring and evaluation, review and development**

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<sup>44</sup> (Fitzsimons, 2012)

<sup>45</sup> (Taylor & Taylor, 2013)

<sup>46</sup> (Cambridge, 2008)

<sup>47</sup> (Cocks et al., 2009; Parsons et al., 2009; Towers & Wilkinson, 2014)

<sup>48</sup> (Taylor & Taylor, 2013; Van Ingen, Moore, & Fuemmeler, 2008)

<sup>49</sup> (Heller & Schindler, 2009)

<sup>50</sup> (Towers & Wilkinson, 2014)

<sup>51</sup> (Parsons et al., 2009)

<sup>52</sup> (Heller & Caldwell, 2006; Walker, 2012)



The literature recommends that plans should be measurable, with a clear implementation strategy and assigned responsibility for implementing the strategy.<sup>53</sup> Priority should be given to what happens after a PCP meeting takes place, including regular meetings and reviews.<sup>54</sup> Quality of life measures have been recommended to measure personal outcomes.<sup>55</sup>

## **1.2. Evidence available on the effectiveness and implementation of PCP**

Despite the international research and policy endorsement of PCP and person centredness, most of the scientific literature focuses on its use and best practices but there is a lack of attention to its effectiveness.<sup>56</sup> The literature reviewed has identified a number of problems in relation to PCP outcomes. To address these, it has been recommended that as well as plans being developed, quality, content, process, and life-style related outcomes should be in place.<sup>57</sup> The literature has identified two types of outcomes: indirectly resulting from participation in PCP and targeted in PCP.

- This review found indirect benefits resulting from participation in PCP. Participation in PCP results in an increased number of activities, opportunities and personal benefits in terms of happiness, self-determination and self-esteem for the person who is the focus of the PCP.<sup>58</sup> Aspects of PCP also improve through the process, for example, communication, involvement and teamwork.<sup>59</sup> These aspects are not usually targeted as PCP goals.
- This report focuses on outcomes targeted in PCP including out of school transition outcomes, transition into older adulthood, social inclusion, independence, and positive risk taking. These findings are presented in the following sections (1.2.1-1.2.5).

### **1.2.1. Out of school transition**

Personal characteristics as well as school practices predict successful post-school outcomes.<sup>60</sup> Within school practices, multi-stage transition programmes including preparation, PCP, and implementation have been reported to lead to successful outcomes for people with intellectual disabilities and autism spectrum disorder.<sup>61</sup> The PCP meeting in itself is not enough to accomplish goals.<sup>62</sup>

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<sup>53</sup> (Robertson & Emerson, 2007)

<sup>54</sup>(Hagner et al., 2012; Hagner et al., 2014; Wehmeyer et al., 2006)

<sup>55</sup> (Claes et al., 2012; Verdugo, Navas, Gómez, & Schallock, 2012)

<sup>56</sup> (Claes, Van Hove, Vandeveld, van Loon, & Schallock, 2010; Dowling et al., 2007; Parsons et al., 2009; Robertson & Emerson, 2007; Robertson et al., 2006; Taylor & Taylor, 2013)

<sup>57</sup> (Robertson & Emerson, 2007)

<sup>58</sup> (Claes et al., 2010; Espiner & Hartnett, 2012; Robertson et al., 2006; Wehmeyer et al., 2006)

<sup>59</sup> (Claes et al., 2010)

<sup>60</sup> (Papay & Bambara, 2014)

<sup>61</sup> (Hagner et al., 2012; Wehmeyer et al., 2006)

<sup>62</sup> (Kaehne & Beyer, 2014)



### **1.2.2. Transition into older adulthood**

The research reviewed suggests that both people with disabilities and their caregivers should be involved in planning.<sup>63</sup> Despite concerns they have about planning, both groups have clear preferences for their futures.<sup>64</sup> An effective PCP peer-support intervention conducted with people with intellectual disabilities and their caregivers resulted in a decrease of caregivers' burden and in an increase in the opportunities for daily choice making.<sup>65</sup> The intervention consisted of legal and financial training and workshops focused on planning. Although without empirical validation, another PCP model has been proposed for people with intellectual disability and dementia. The model is based on:

- The flexibility of families and professionals to lead the process
- The person as the focus of the plan
- Developing emergency plans and providing informal support.<sup>66</sup>

### **1.2.3. Social inclusion**

Social inclusion involves access to the community, experience of social roles and recognition of one's competence, and development of social networks.<sup>67</sup> The literature review findings indicate that there are moderate changes in social and community inclusion resulting from PCP.<sup>68</sup> Goal setting and circles of support, although both are key components of PCP, have been used as independent strategies to achieve social and community inclusion. Goal setting interventions result in moderate changes in community inclusion<sup>69</sup> and the evidence is weaker in relation to circles of support.<sup>70</sup> However, circles of support are considered a very important resource for community inclusion.<sup>71</sup>

PCP has an impact in social networks, contact with friends and family, community based activities, scheduled activities and choice.<sup>72</sup> However, these results cannot be generalised to different groups of people with disabilities (for example, people with autism, mental health, behavioural or emotional problems).<sup>73</sup> PCP has been found to be helpful but not sufficient to promote social inclusion.<sup>74</sup> Approaches to increase

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<sup>63</sup> (Bowey & McGlaughlin, 2007; Craig & Cartwright, 2015; Heller & Caldwell, 2006; Taggart & Trainor, 2012)

<sup>64</sup> (Bowey & McGlaughlin, 2007; Craig & Collen Cartwright, 2015; Heller & Caldwell, 2006; Taggart & Trainor, 2012)

<sup>65</sup> (Heller & Caldwell, 2006)

<sup>66</sup> (Towers & Wilkinson, 2014)

<sup>67</sup> (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012)

<sup>68</sup> (Claes et al., 2010; Robertson et al., 2006)

<sup>69</sup> (McConkey & Collins, 2010; Mirza & Hammel, 2009)

<sup>70</sup> (Wistow, Perkins, Knapp, Bauer, & Bonin, 2016)

<sup>71</sup> (Wistow et al., 2016)

<sup>72</sup> (Robertson et al., 2006)

<sup>73</sup> (Robertson et al., 2007)

<sup>74</sup> (Robertson et al., 2006)



community inclusion need to focus on naturally occurring opportunities for social interaction to increase the social networks of people with intellectual disabilities.<sup>75</sup>

Goal setting has also been reported as a strategy to increase community inclusion. Goal setting, with the key role of support staff, can enable some people with intellectual disabilities living in residential settings to participate in more social activities.<sup>76</sup> Goal setting within systems level advocacy, and using assistive devices, has also been reported as successful in removing environmental barriers.<sup>77</sup>

Despite the scarce evidence on the effectiveness of circles of support, a study identified that circles of support were seen as a key factor enabling individuals to live well in their communities and participants with intellectual disabilities universally attributed their quality of life to their respective circle.<sup>78</sup> Circles have been found to be used to help people with intellectual disabilities have their rights respected.<sup>79</sup>

#### **1.2.4. Independence**

Independence has been reported as one of the main benefits resulting from participation in PCP.<sup>80</sup> There is also agreement that PCP provides opportunities for people with intellectual disabilities to set goals to achieve independence.<sup>81</sup> The findings of this literature review indicate that goals that focus on developing skills (for example, employment, finances and communication) lead to increased ability to live more independently.<sup>82</sup> Individualised funding has also been found to be facilitative of independence in choice making for services.<sup>83</sup>

Independence, nonetheless, is conditioned by a number of factors. For example, the availability of services, a limited choice of day services, a limited choice of housing, waiting lists for services, limited employment opportunities and the choices offered by staff can limit the opportunities of people to live more independently.<sup>84</sup>

Independence is also conditioned by the accessibility of information and processes which can enable adults with intellectual disabilities to participate in the PCP process.<sup>85</sup> Person-centred funding has also been associated with increased self-determination

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<sup>75</sup> (Robertson et al., 2006)

<sup>76</sup> (McConkey and Collins (2010)

<sup>77</sup> (Mirza & Hammel, 2009)

<sup>78</sup> (Wistow et al., 2016)

<sup>79</sup> (Hillman et al., 2012)

<sup>80</sup> (Wigham et al., 2008)

<sup>81</sup> (McCarron et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006; Sheerin, Griffiths, de Vries, & Keenan, 2015; Wigham et al., 2008)

<sup>82</sup> (Lawlor, Spitz, York, & Harvey, 2013)

<sup>83</sup> (Kirkman, 2010)

<sup>84</sup> (Robertson et al., 2007)

<sup>85</sup> (Espiner & Hartnett, 2012)



and community participation.<sup>86</sup> Lastly, the role of staff and informal support has been identified to enable the accomplishment of independence-related goals.<sup>87</sup>

### **1.2.5. Positive risk taking**

As the independence of people with disabilities increases, so too does the perceived risk associated with this independence.<sup>88</sup> However, there are two major challenges to positive risk taking: organisational policies and staff concerns about risk.<sup>89</sup> Management of positive risk taking involves a reformulation of organisational policies that empower people to develop skills to manage their risks and to take responsibility for them, and a review of staff's attitudes towards independence and risk.<sup>90</sup>

## **1.3. Evidence on models of best practice in relation to an exploration of employment**

Research illustrated that PCP is best delivered along with, and connected to, other complementary strategies including job development and long-term supports (including job related and community related). PCP is a common element of two extended modalities of individualised employment support for people with disabilities: supported employment and customised employment.<sup>91</sup> Supported employment consists of the provision of individualised support for people with disabilities to gain and maintain employment and the provision of support to the employer.<sup>92</sup> Customised employment is used with people with more significant disabilities. It is based on the needs, strengths and interests of the person with a disability and aims to meet the business needs of the employer.<sup>93</sup> Although PCP is widely used for the exploration of employment, there is a reported inconsistency on the effectiveness of PCP in achieving employment outcomes.<sup>94</sup> There is also a lack of empirical evidence that evaluates the effectiveness of interventions based on the modalities of supported and customised employment.<sup>95</sup> A number of PCP models/best practices for an exploration of employment that can be used within supported employment and customised employment modalities are described next.

### **1.3.1. Getting to know the person and job seeker profile development**

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<sup>86</sup> (Kirkman, 2010)

<sup>87</sup> (Fitzsimons, 2012; García Iriarte, 2009; McCarron et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006; Sheerin et al., 2015)

<sup>88</sup> (Robertson et al., 2006)

<sup>89</sup> (Hillman et al., 2012)

<sup>90</sup> (Hillman et al., 2012)

<sup>91</sup> (Pectu, Chezan, & Van Horn, 2015)

<sup>92</sup> (European Commission, 2011)

<sup>93</sup> (Riesen, Morgan, & Griffin, 2015)

<sup>94</sup> (Claes et al., 2010; Robertson et al., 2006)

<sup>95</sup> (Hendricks, 2010)



This first step consists of gathering information about the person, their interests, needs and skills. Customised employment uses the Discovery method and supported employment develops a job seeker profile. For people with more significant disabilities who have limited experience of decision making, Cobigo and colleagues recommend that they are given the opportunities to choose between job-related tasks until there is enough evidence of what their preferences are.<sup>96</sup>

### **1.3.2. Planning**

A second step is planning. The only planning model with empirical support found in this literature review is the Self-Determined Career Development Model. It is a model to develop problem solving skills and to help set and attain career related goals.<sup>97</sup> It involves a three-stage process of goal setting, self-monitoring plan and self-evaluation. The model has been used to achieve employment<sup>98</sup> and within employment to teach problem solving skills.<sup>99</sup>

The literature has found other forms of planning. For example, in an intervention by Carter, Trainor, Ditchman, Swedeen, and Owens that focused on obtaining summer jobs, the planning involved the facilitator and the person with a disability, and it aimed to connect summer jobs with long term career goals.<sup>100</sup> A planning tool template was used that guided the plan to identify goals, supports, potential job opportunities, and assign responsibilities. The Individualized Career Planning Model develops a “road-map” that results in having a representational portfolio that can be used to approach employers.<sup>101</sup> Planning is also used to identify what modality of employment is most adequate.<sup>102</sup> In the Beyond High School process, students take the lead and are actively involved in tasks that would generally be the responsibility of the job developer.<sup>103</sup>

### **1.3.3. Involvement of the community**

The community has been traditionally identified as having a key role in helping people to gain employment.<sup>104</sup> In a recent intervention, the community was mobilised to develop employment opportunities.<sup>105</sup> The latter was achieved through “community conversations”, in which participants identified what the community and individuals could do to improve employment, and through “resource mapping”, in which information about employment and support was identified.

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<sup>96</sup> (Cobigo, Morin, & Lachapelle, 2007)

<sup>97</sup> (Devlin, 2008; Wehmeyer et al., 2009)

<sup>98</sup> (Wehmeyer et al., 2009)

<sup>99</sup> (Devlin, 2008)

<sup>100</sup> (Carter, Trainor, Ditchman, Swedeen, & Owens, 2009)

<sup>101</sup> (Condon & Callahan, 2008)

<sup>102</sup> (Blessing, 2014)

<sup>103</sup> (Wehmeyer et al., 2006)

<sup>104</sup> (Lynas, 2014; Vera, 2014)

<sup>105</sup> (Carter et al., 2009)





### **1.3.4. Roles and training**

The main role in the exploration of employment is that of the employment specialist (for example, a job coach or a job developer).<sup>106</sup> They are responsible for plan facilitation, getting to know the person, developing relationships and negotiating with employers. Harvey identified the following competencies for successful employment specialists:

- Positive and open approach to life
- Customised job development
- Respecting and relating to others
- Business and employment practices
- Business networking
- Collecting, interpreting and using information
- Communicating with others
- Planning and organising.<sup>107</sup>

In one of the interventions reviewed, the role of “employer liaisons” was taken by community members (for example, employers) to develop links with the community and to link with the employment specialist.<sup>108</sup>

### **1.3.5. State level strategies**

Based on a study of three US States with high levels of integrated employment, Cohen Hall, Butterworth, Winsor, Gilmore, and Metzel identified key aspects to this success:

- State-wide training on values
- A network of key players who are committed to the system and work together
- Goal clarity at a systemic level.<sup>109</sup>

### **1.3.6. Other supported employment activities**

The following strategies have been found to be complementary of PCP for the exploration of employment:

- Job development and career search
- Placement
- Training
- Long-term support
- Positive behavioral intervention.

## **1.4. Challenges to the effective implementation of PCP**

### **1.4.1. Transforming services culture**

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<sup>106</sup> (Mank & Grossi, 2013)

<sup>107</sup> (Harvey, Szoc, Dela Rosa, Pohl, & Jenkins, 2013)

<sup>108</sup> (Carter et al., 2009)

<sup>109</sup> (Hall, Butterworth, Winsor, Gilmore, & Metzel, 2007)



This is one of the most inhibiting factors of PCP.<sup>110</sup> Flexible support is difficult in large traditional services.<sup>111</sup>

#### **1.4.1.1. Standardisation of PCP**

Organisations have approached the implementation of PCP through standardised strategies that challenge the individualisation and core principles of PCP.<sup>112</sup>

#### **1.4.2. Services accountability to persons with disabilities and to funders**

An excessive reliance of services on activities and reporting can result in a lack of attention to people's goals and their accomplishment.<sup>113</sup> The challenge for services is to become accountable to people with disabilities for the achievement of their personal outcomes. For regulatory bodies and funders the challenge is to harmonise their quality criteria with the achievement of individualised outcomes.

#### **1.4.3. Limited choice for people with intellectual disabilities**

The choices of people with intellectual disabilities are limited by various factors: a lack of person centredness, a top down approach, conservative risk assessment, community barriers and systematic barriers (for example, lack of employment opportunities).<sup>114</sup>

#### **1.4.4. Coordination of inter-agency and natural support**

Service infrastructure has been identified as a challenge to PCP. It has been also found that it is difficult to establish circles of support and relying on a community base in an individualistic society.<sup>115</sup>

#### **1.4.5. Over-reliance on tools**

The focus of PCP should be on quality processes and outcomes rather than on the tools used to carry out PCP.<sup>116</sup>

#### **1.4.6. Practicalities of planning**

The lack of a PCP facilitator has resulted in people not having a plan.<sup>117</sup> Other challenges involve organising people and venues, scheduling constraints and planning in reaction to crisis.<sup>118</sup>

#### **1.4.7. Personal factors**

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<sup>110</sup> (Cambridge & Carnaby, 2005; Dowling et al., 2007)

<sup>111</sup> (Claes et al., 2010; Dowling et al., 2007)

<sup>112</sup> (Parsons et al., 2009)

<sup>113</sup> (García Iriarte, In press)

<sup>114</sup> (Parsons et al., 2009; Robertson & Emerson, 2007)

<sup>115</sup> (Dowling et al., 2007)

<sup>116</sup> (Parsons et al., 2009)

<sup>117</sup> (Robertson et al., 2007)

<sup>118</sup> (Parsons et al., 2009)



Involving groups of people with certain characteristics has been found to be a challenge, for example, people from ethnically different groups.<sup>119</sup> Also people with autism or mental health problems are less likely to receive PCP and if they have PCP, they benefit less from it.<sup>120</sup>

#### **1.4.8. Resources**

Inflexible funding structures have been found to be a challenge to the implementation of PCP.<sup>121</sup> Limited funding also poses challenges to sustain change.<sup>122</sup>

### **1.5. Recommendations for the implementation of PCP**

In conclusion, the findings of this literature review resonate with previous findings in that there is scarce empirical evidence supporting PCP as best practice to accomplish individual outcomes. Moderate effectiveness has been reported in relation to out of school transition, community inclusion and achieving independence. The findings indicate that for adequate implementation, PCP should:

#### **1.5.1. Be supported by a person-centred culture in each organisation**

- Ensure organisations implementing PCP adopt it at the organisational level.

#### **1.5.2. Be approached from an advocacy perspective**

- PCP should be considered a form of self-advocacy
- Organisations advocate for wider systems change to improve community inclusion, afford people with disabilities more independence and enhance opportunities for education and employment.

#### **1.5.3. Prioritise individual outcomes and services accountability to individuals**

- Include life goals and not be constrained by the services provided by an organisation
- Be a three-stage process involving preparation and training, facilitation of meetings, and the implementation of plans and follow up
- Be flexible, incorporating services from a range of providers, to accomplish goals
- Be governed by policies and regulations that make organisations accountable for individuals' goal accomplishment.

#### **1.5.4. Involve the person and the family, paid staff and natural support**

- Provide individualised support to people with disabilities to participate in the planning (for example, an independent advocate)
- Involve an experienced facilitator in PCP who ensures independence from the organisation if PCP is facilitated within an organisation
- Involve paid staff implementing the plans in the planning process.

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<sup>119</sup> (Claes et al., 2010)

<sup>120</sup> (Robertson et al., 2007)

<sup>121</sup> (Dowling et al., 2007)

<sup>122</sup> (Walker, 2012)



### **1.5.5. Provide training to all involved**

- Each group should have customised training, for example, people with disabilities on choice making and self-advocacy, and paid staff on PCP facilitation, implementation and human rights.

### **1.5.6. Provide the person and the family with authority over the plans**

- Conduct PCP in an informal way to empower the person and the family.

### **1.5.7. Be used for an exploration of employment alongside other strategies**

- Start exploration of employment by getting to know the person and assess work preferences directly with them
- Involve community stakeholders in planning
- Connect individual approaches to system level strategies to work towards the same goals of employment
- Train people with disabilities in problem solving skills, self-monitoring and self-evaluation.



## 2. Background

This literature review on person-centred planning (PCP) was commissioned by the Health Service Executive (HSE) and the National Disability Authority (NDA) in March 2016 to inform the development of a national framework on PCP across services provided to adults with disabilities in Ireland. Two further pieces of work have been commissioned by the HSE and the NDA to inform the development of the national framework: case study research on the implementation of PCP, and an evaluation of inspection reports conducted by the Health Information and Quality Authority in residential services with a focus on PCP.

The development of a PCP national framework for services provided to adults with disabilities results from the implementation of a major programme of disability service reform entitled “Transforming lives”, which underpins the New Directions model of personal support. The Transforming Lives programme focuses on supporting people to live the lives they choose in the community and to use person-centred supports. New Directions proposes that adults with disabilities have the widest possible choices and options to live in their communities and use community support.<sup>123</sup> This policy represents a radical shift from congregated and organisation-led services to community and individualised supports. Underpinning the changes that adult disability services in Ireland need to undertake is a person-centred vision of services and support where the person with a disability is at the centre of the service provision and leads the support towards the accomplishment of meaningful personal outcomes. The new policy identifies twelve support areas that should be available to people with disabilities for:

- Making choices and plans
- Making transitions and progression
- Inclusion in one’s local community
- Accessing education and formal learning
- Maximising independence
- Personal and social development
- Health and wellbeing
- Accessing bridging programmes to vocational training
- Accessing vocational training and work opportunities
- Personal expression and creativity
- Having meaningful social roles
- Influencing service policy and practice.

Although there is no consensus on the definition of PCP in the international literature,<sup>124</sup> the National Disability Authority 2005 guidelines define PCP as “a way of discovering how a person wants to live their life and what is required to make that

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<sup>123</sup> (Health Service Executive, 2012)

<sup>124</sup> (Claes et al., 2010; Taylor & Taylor, 2013)



possible” (p. 12).<sup>125</sup> The overall aim of PCP is positive change in people’s lives and services.<sup>126</sup> Person centredness underpins PCP. In the NDA guidelines, person centredness is defined as “seeking to put the person first” (p. 13), and it is identified as a useful means of driving the PCP process.<sup>127</sup>

## 2.1. Historical development of PCP

PCP was first formulated in North America<sup>128</sup> and, according to Cambridge and Carnaby, it has evolved from:

- Normalisation, social role valorisation, self-determination and social inclusion theories
- An ordinary life (comprehensive community based residential services for people with “mental handicap”) proposed by the King’s Fund Centre in 1980
- The five service accomplishments developed by O’Brien in the 1980s.<sup>129</sup>

Normalisation and social role valorisation emphasise “equality of respect, opportunity, and life choices with the nondisabled population, and to gain access to mainstream public services” (p. 179).<sup>130</sup> Along with the role of disability activism, the application of these theories has resulted in different strategies for service planning and delivery including PCP, direct payments, self-directed supports and consumer-directed supports.<sup>131</sup>

The development of PCP, and previously, individualised planning, goes in tandem with the transition from institutional care to community living in the last quarter of the twentieth century.<sup>132</sup> Individualised systems of service planning have been therefore developing since the 1980s.<sup>133</sup> These initial forms of planning were criticised because of their focus on individuals’ skills and behaviour rather than on individuals’ life aspirations (for example, individual service planning, individual programme planning, goal planning, case review and needs planning, and shared action planning).<sup>134</sup> In 1985, the general term person centred planning emerged.<sup>135</sup> Specific tools to implement PCP were developed including Lifestyles Planning, Goal Planning, Essential Lifestyle

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<sup>125</sup> (National Disability Authority, 2005)

<sup>126</sup> (National Disability Authority, 2005)

<sup>127</sup> (National Disability Authority, 2005)

<sup>128</sup> (Cambridge, 2008)

<sup>129</sup> (Cambridge & Carnaby, 2005)

<sup>130</sup> (Cumella, 2008)

<sup>131</sup> (Cumella, 2008)

<sup>132</sup> (Parsons et al., 2009)

<sup>133</sup> (Cambridge, 2008)

<sup>134</sup> (Cambridge, 2008)

<sup>135</sup> (Claes et al., 2010)



Planning, MAPS, Planning Alternative Tomorrows with Hope (PATH), and Personal Futures Planning.<sup>136</sup>

For the last four decades, PCP has been particularly implemented in organisations providing services to people with intellectual disabilities. A set of guidelines on PCP principles and implementation were published in 2005 by the NDA to provide a unified approach on the implementation principles and key components of PCP in Ireland.<sup>137</sup> However, person-centred and individualised approaches to disability service provision have flourished internationally over the last ten years, and numerous research papers have been published accordingly. It is against this background that the NDA and HSE commissioned this literature review, to examine the current evidence base on PCP in the international literature and to inform the development of a national framework for PCP. Before the findings of the literature review are reported, the next section presents some common areas of misunderstanding in relation to PCP.

## **2.2. Common areas of misunderstanding in relation to PCP**

Some of the common areas of misunderstanding identified in the literature involve the relationship between PCP and person-centred active support, the difference between PCP and care management, the uniqueness of PCP in relation to earlier approaches to planning such as individual needs planning, differences from individual educational planning, and more recent approaches to the provision of services such as personalisation.

### **2.2.1. Active support plans**

Active support plans are about the everyday micro-planning of activities and support and are person-centred.<sup>138</sup> Together with PCP, active support can provide a high quality support to individuals with intellectual disabilities.<sup>139</sup> One of the challenges identified by Jones and Lowe in relation to the implementation of PCP is that for people who have been prevented from participating in everyday activities, active support offers the opportunity to participate and person-centred assistance to participate successfully.<sup>140</sup> For people who have spent their lives with minimal activity, identifying their preferred activities may be an impossible task. Active support could enable the supportive environment to introduce PCP.<sup>141</sup>

### **2.2.2. Care management plans**

A common challenge implementing PCP is to understand how person centred plans fit into care management plans and support plans. Care management was the strategy developed to provide care to people in the community in the broader process of de-

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<sup>136</sup> (Cambridge, 2008; Claes et al., 2010; Parsons et al., 2009)

<sup>137</sup> (National Disability Authority, 2005)

<sup>138</sup> (Jones & Lowe, 2008)

<sup>139</sup> (Jones & Lowe, 2008)

<sup>140</sup> (Jones & Lowe, 2008)

<sup>141</sup> (Jones & Lowe, 2008)



institutionalisation and it should be responsive to PCP.<sup>142</sup> Case management is the service system approach to provide individual support to people with intellectual disabilities.<sup>143</sup> In the UK and Australia, these functions involve assessment, planning and prioritization of needs allocation, development and negotiation of resources; and implementation, monitoring and review of support plans.<sup>144</sup> These can be professionally-managed or person/family-led where they implement and manage a support plan by administering their own funds.<sup>145</sup>

Bigby, Fyffe, and Ozanne outline key differences between PCP and a care management plan:

- PCP is a comprehensive approach to a person's life, needs and hopes while a care management plan links needs assessment to services and is resource-based
- Person centredness underpins PCP but not care management.<sup>146</sup>

Another key feature of PCP is that it marshals both paid and natural support.<sup>147</sup> Cambridge proposes a model of PCP underlying case management where the care manager gets to know and understand the person, their families and sources of support, has smaller caseloads and access to formal and natural support.<sup>148</sup>

### **2.2.3. Earlier approaches to planning**

A 2004 work cited by Taylor and Taylor stated that the differences between earlier models of planning (for example, individual needs planning, individual service planning) and person-centred planning are that in PCP: <sup>149</sup>

- The person who is the focus of the plan, rather than professionals, controls the plan
- PCP relies on both natural supports and paid supports
- Organisations adapt to the needs of individuals rather than fitting them within existing programmes.

PCP is more focused on the strengths of the person and incorporates services and support outside the organisation service system facilitating the planning.<sup>150</sup>

### **2.2.4. Individualised Education Plans**

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<sup>142</sup> (Cambridge, 2008)

<sup>143</sup> (Robertson & Emerson, 2007)

<sup>144</sup> (Robertson & Emerson, 2007)

<sup>145</sup> (Robertson & Emerson, 2007)

<sup>146</sup> (Bigby et al., 2007)

<sup>147</sup> (Brechin, 2005; Cambridge, 2008; Xie, Hughes, Challis, Stewart, & Cambridge, 2008)

<sup>148</sup> (Cambridge, 2008)

<sup>149</sup> (Taylor & Taylor, 2013)

<sup>150</sup> (Taylor & Taylor, 2013)





Individualised education plans are widely used in educational settings. Individualised Education Plans and PCP share some common values and elements:<sup>151</sup>

- Team approach
- Person centredness
- Long and short term goals
- Identification of supports and methods of evaluation.

However, PCP takes a wider and longer term view than an individual education plan and, according to Meadan, Sheldon, and DeGrazia, PCP should inform the individual education plan.<sup>152</sup>

### **2.2.5. Personalisation**

The Scottish Government defined personalisation in 2006 as putting the person at the centre as a participant in shaping the services they get and allowing them to work with professionals and their carers to manage risk and resources (cited in Harkes, Brown and Horsburgh<sup>153</sup>). In an Irish context, Genio defined personalised or individualised supports as those which address the unique needs of the individual focusing on their strengths and abilities, which are chosen by the person and which are delivered in the community fostering inclusion and participation.<sup>154</sup> McConkey and Keogh argue that personalisation is a step further than PCP in providing individualised services to people with intellectual disabilities. According to these authors, services adopting PCP have struggled to become truly personalised as they have kept their same core culture and ethos.<sup>155</sup> McConkey and Keogh state that personalisation “demands a revolution in our thinking about supports and services” (p. 97). The key characteristics of personalisation are an emphasis on self-determination and tailoring supports around the specific needs of the person. Personalised or individualised supports have been described in the following way:<sup>156</sup>

- “Planned and delivered on the basis of a consideration of the wider needs and potential contributions of the person, moving away from a focus on deficits
- A response to one person rather than group-based
- Chosen by the person with a disability or mental health difficulty (or their advocate as appropriate)
- Delivered in the community fostering inclusion and participation rather than in segregated, stigmatising settings
- Inclusive of family and community supports and mainstream services
- Reliant on paid professionals only when necessary
- Cost-effective and represent good value for money” (p. 4)

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<sup>151</sup> (Meadan et al., 2010)

<sup>152</sup> (Meadan et al., 2010)

<sup>153</sup> (Harkes, Brown, & Horsburgh, 2014)

<sup>154</sup> (Genio, 2012)

<sup>155</sup> (McConkey & Keogh, 2016)

<sup>156</sup> (Genio, 2012)



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McConkey and Keogh add to the above factors the relevance of partnerships and novel approaches such as circles of support and peer advocacy.<sup>157</sup> One of the barriers to achieve personalisation involves access to individualised funding where the individual has control over the services and supports acquired.<sup>158</sup> Kirkman concurs that person-centred funding or individualised funding is one way to enable flexibility for self-determination and community participation of people with disabilities.<sup>159</sup> Individualised funding models are prominent in the UK, Germany, Canada, the Netherlands, Sweden, some States in the US and Australia.<sup>160</sup>

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<sup>157</sup> (McConkey & Keogh, 2016)

<sup>158</sup> (McConkey & Keogh, 2016)

<sup>159</sup> (Kirkman, 2010)

<sup>160</sup> (Kirkman, 2010)



### 3. Literature review aims

This literature review aims to identify available evidence in the area of PCP to inform the development of a national framework. Specifically, the objectives of the literature review are to:

- Provide an analysis of the key elements of good practice included in the guidelines on PCP<sup>161</sup>
- Examine the available evidence since 2005 and identify the key elements and principles of good practice in PCP that should be included in a PCP framework and
- Assess models of good practice in PCP for an exploration of employment.

The literature review pays specific attention to the development and implementation of PCP and to systemic factors that influence the PCP process, such as policies, quality systems, and organisational culture.

The review focuses primarily on intellectual disability (including dual diagnosis of intellectual disability and mental health problems), autism, and to a lesser extent, physical and sensory disability. The main focus of this literature review is adults older than 18 years of age who are receiving a variety of services such as day, residential, respite, or various types of personal assistance, but also includes research on the transition to adulthood, conducted with youth before they reach 18 years of age.

The following questions have guided the literature review:

1. What evidence is available on the use of the key elements identified in the 2005 NDA guidelines?
2. What evidence is available since 2005 on the implementation and effectiveness of PCP?
3. What are models of best PCP practice for an exploration of employment as part of the PCP process?
4. What are the key challenges to the effective implementation of PCP?
5. What are best PCP implementation practices?<sup>162</sup>
6. What are recommendations to implement PCP?

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<sup>161</sup> (National Disability Authority, 2005)

<sup>162</sup> Best practices are presented throughout the report rather than in a specific section.



## 4. Methodology

The literature review was conducted through a search procedure of relevant databases by a team of researchers and in consultation with a panel of experts.<sup>163</sup> Following Dowling, Manthorpe and Cowley, we conducted an integrative review with the aim to seek consensus rather than a systematic review and used broad inclusion criteria of published sources.<sup>164</sup> These sources included empirical work, literature reviews, discussion and evaluation papers.

The following electronic databases were searched using key words and related words through various searchable combinations (see Table 4.1): Web of Science, Psychinfo, Cinhal, Pubmed, Embase, Eric and Proquest Dissertations. The search was filtered by years (2005-2016), full text, published books and peer-reviewed journals in English. Searches in widely available search engines such as Google and Google Scholar were conducted. This was followed by manual searches of relevant journals. Reference lists were also checked for relevant citations. The data was managed through EndNote X7, a reference manager software.

Abstracts and executive summaries of sources were initially reviewed to ensure they provided evidence of the specific search terms. If the abstract/executive summary indicated relevance to the key terms, the full source was reviewed. When no relevance to the literature review was apparent from the abstract or executive summary, the source was discarded. The database searches generated in excess of 400 sources that indicated relevance to the literature review through the abstract and/or executive summary. These were fully reviewed.

Sources were doubled-checked by two members of the research team for relevance to answer the literature review questions. Preliminary findings were presented to members of the NDA, the HSE and the New Directions Working subgroup on PCP who provided suggestions for further analysis of the data in relation to a number of areas, such as common misunderstandings and the role of facilitators. Members of the expert panel provided feedback on the project methodology and on previous drafts of this report.

The research team employed the Human Rights Based Approach to disability to conduct this literature review. Ireland is in the process of ratifying the United Nations Convention on the Rights of Persons with disabilities (UNCRPD).<sup>165</sup> The UNCRPD adopts a social model and human rights based approach that understands disability as the interaction between persons with impairments and environmental barriers that limit their participation on an equal basis to others. Specifically, the

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<sup>163</sup> Members of the expert panel included: Prof. Tamar Heller, University of Illinois at Chicago, Prof. Miguel Ángel Verdugo, University of Salamanca, Prof. Patricia O'Brien, University of Sydney

<sup>164</sup> (Dowling et al., 2007)

<sup>165</sup> (United Nations, 2006)



following premises informed the assumptions that guided our decisions through the process of reviewing the literature and writing the report:

- Difference is inherent to the human condition
- Contributions from all persons help diversify the human experience and
- Society should provide equal opportunities for all members to exercise their rights.<sup>166</sup>

**Table 4.1. Key terms and variations**

Key terms	Variations
Education	"learning" OR "course" OR "literacy"
Employment	"work" OR "job" OR "supported employment" OR "vocational rehabilitation" OR "voluntary"
Independence	"autonomy" OR "decision-making" OR "choice"
Intellectual disability	"learning disabilit*" OR "developmental disabilit*"
Other impairments	"Autism Spectrum Disorder" OR "ASD" OR "physical disabilit*" OR "sensory disabilit*" OR "communication difficult*"
Person centred planning	"PCP" OR "person centredness"
Risk	
Social inclusion	"community" OR "mainstream services" OR "mainstream community" OR "community participation"
Social Roles	"occupation"
Transition	

<sup>166</sup> (Rioux & Carbert, 2003)



## 5. What evidence is available on the use of the key elements identified in the 2005 NDA guidelines?

The key elements of PCP identified in the National Disability Authority 2005 guidelines include:<sup>167</sup>

1. Establishing a framework
2. Clarifying roles and responsibilities and identifying any training and support that will be required
3. Identifying plan-facilitators and ensuring that they are adequately trained, experienced and supported
4. Establishing mechanisms of ongoing communication, plan management and the monitoring, evaluation, review and development of the PCP process.

### 5.1. Establishing a framework for PCP

Establishing a framework involves:

- Encouraging people and all around them to develop a positive view of themselves, their lives and their futures
- Empowering people with disabilities and their parents/family to take control of their lives; respecting the natural authority of the person and the families
- Working towards facilitating people with disabilities to say how they want to live their lives and what help, opportunities, and development of local capacities would make a contribution to change
- Working towards specialist disability services building a person-centred culture and sustaining it
- Working more generally on developing an overall climate that is supportive of people with disabilities becoming fully part of, benefiting from and making contributions to their local communities.

#### 5.1.1. Encouraging people and all around them to develop a positive view of themselves, their lives and their futures

There is consensus in the literature reviewed on the need to involve the person who is the focus of PCP as well as their advocates in thinking about their futures, aspirations, needs and preferences, and a commitment to action.<sup>168</sup> Recommendations emerging from the literature also indicate that planning should be approached with the intention of improving the life of the person.<sup>169</sup> Recommended strategies to

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<sup>167</sup> The four key elements have been adapted to facilitate the report of the literature review findings. In this report, the roles and responsibilities of all stakeholders (also plan facilitators) have been included under section 5.2. “clarifying roles and responsibilities”. Training needs of all stakeholders (also plan facilitators) have been included under section 5.3. “identifying training and support that will be required”.

<sup>168</sup> (Cambridge & Carnaby, 2005; Clark, Garland, & Williams, 2005; Dowling et al., 2007; Espiner & Hartnett, 2012; Fitzsimons, 2012; García Iriarte, 2009; Parsons et al., 2009; Taylor & Taylor, 2013)

<sup>169</sup> (Parsons et al., 2009)



develop a positive view of people with intellectual disabilities include: preparation, training, and self-advocacy.

The literature on transition provides evidence of how training, preparation and skills building before PCP have resulted in an enhanced sense of autonomy of participants with intellectual disabilities.<sup>170</sup> In a study of a three-stage process with people with intellectual disabilities including preparation, PCP meeting and follow up, the intervention resulted in increases in participants' positive expectations, self-determination, career decision making and autonomy.<sup>171</sup>

### **5.1.2. Empowering people with disabilities and their parents/family to take control of their lives; respecting the natural authority of the person and the families**

Vesting power to people with disabilities and their families to drive the process is agreed as a key factor in the success of PCP.<sup>172</sup> This requires firstly, that the person who is the focus of the plan and their family are present and contribute to the process.<sup>173</sup> Parsons, Cocks and Williamson note that the person is important, deserves the respect of being included, and has something to contribute to shaping their future.<sup>174</sup> Secondly, it requires that organisations incorporate the decisions that people and their families make into the plan.<sup>175</sup> Fitzsimons, for example, observed that there was a positive relationship between the position in the hierarchy of the organisation that the staff facilitating the plan occupied and the implementation of plans.<sup>176</sup> The higher the staff members were in the hierarchy of the organisation, the more likely it was that plans were implemented. There also needs to be opportunities provided through policies, resources, and supports for empowering individuals and families. For example, Cook and Boaden indicated that families should have substantial influence over the support arrangements in residential settings for people with intellectual disabilities.<sup>177</sup>

Additional strategies recommended to respect the natural authority of the person with a disability and the family involve planning through informal environments (for example, maintaining regular conversations about the person's needs over coffee to ensure that they feel comfortable), developing an attitude that acknowledges the person and/or family as the natural authority in regard to the person's life, and through informal relationships.<sup>178</sup> Planning outside services where people may have

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<sup>170</sup> (Wehmeyer et al., 2006)

<sup>171</sup> (Hagner et al., 2012)

<sup>172</sup> (Cambridge & Carnaby, 2005; Robertson & Emmerson, 2007; Taylor & Taylor, 2013)

<sup>173</sup> (Cambridge, 2008)

<sup>174</sup> (Parsons et al., 2009)

<sup>175</sup> (García Iriarte, In press)

<sup>176</sup> (Fitzsimons, 2012)

<sup>177</sup> (Cocks & Boaden, 2011)

<sup>178</sup> (Parsons et al., 2009)



been unable to develop their interests and skills is another recommendation provided by Genio.<sup>179</sup> Implementing these strategies not only requires a change to the development of PCP, but to the organisational approach to person centredness.<sup>180</sup>

The role of parents and other relatives is even more important in planning with people with intellectual disability and dementia as family members would generally have the most detailed knowledge of the person.<sup>181</sup> Towers and Wilkinson advocate for the involvement of families along with professionals in the planning of services and supports to provide them with a sense of continuity, especially if changes occur in carers or accommodation.<sup>182</sup>

Some researchers state that PCP can be seen as a form of self-advocacy for people with intellectual disabilities to ensure plans are focused on their goals and lead to goal accomplishment.<sup>183</sup> People with disabilities should also be connected with wider self-advocacy groups.<sup>184</sup> Cambridge argues that the self-advocacy function could be extended to the assessment of plans developed in a given organisation for PCP to have maximum impact. For example, people with intellectual disabilities could act as auditors and inspectors of service programmes or be represented on Learning Disability partnership boards, or on the boards of disability specific organisations, which is discussed next.

#### **5.1.2.1. Involvement of people with intellectual disabilities in services/organisations**

This section explores the involvement of people with intellectual disabilities on learning disability partnership boards in the UK and people with intellectual and developmental disabilities on the boards of disability organisations in the USA.

Learning disability partnership boards conduct strategic planning and commissioning of services in the UK, for which they review PCP activities.<sup>185</sup> They represent partnerships between statutory health services, social care agencies, users of services and their families. Partnership boards have to include at least two people with intellectual disability and representatives from other stakeholder groups. A study conducted by Fyson and Fox on the inclusion processes and the achievement of inclusion outcomes found that most partnership boards did not achieve inclusive processes or outcomes.<sup>186</sup> Among the challenges faced by partnership boards were the lack of statutory powers and limited engagement of statutory agencies, and that they were more focused on matters of processes than on outcomes. As suggested by

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<sup>179</sup> (Genio, 2014)

<sup>180</sup> (Walker, 2012)

<sup>181</sup> (Towers & Wilkinson, 2014)

<sup>182</sup> (Towers & Wilkinson, 2014)

<sup>183</sup> (Cambridge & Carnaby, 2005; Mazzotti et al., 2015; Walker, 2012)

<sup>184</sup> (Cambridge & Carnaby, 2005; Walker, 2012)

<sup>185</sup> (Cambridge & Carnaby, 2005; Walker, 2012)

<sup>186</sup> (Fyson & Fox, 2014)





the authors of the study, a balance between ensuring meaningful inclusion of board members and securing an inclusive society for all needs to be achieved.

It is important to note, however, that in a study conducted by Hoole and Morgan only study participants who were members of self-advocacy groups had a vision and willingness to be involved with their organisations.<sup>187</sup> Therefore, self-advocacy skills and human rights awareness may be necessary to increase participation of people with intellectual disabilities in service organisations. Participants in Hoole and Morgan's study attributed their positive experiences with services (for example, day services, support workers, professional services, accessible information and travel training) to feeling listened to and having people advocating on their behalf. They indicated that they held personal power within regular meetings such as house meetings, the local self-advocacy group, and the learning disability partnership board. Greater involvement within services, the authors suggested, could serve to address the power imbalance between staff and people with intellectual disabilities which can lead to feelings of unfairness and inequality. The financial recognition of time given to participation in these meetings was valued by participants. According to Hoole and Morgan, participants expressed willingness for future involvement in services and to advocate on behalf of others:

I have got my annual review... and I'm going to press that the other two of us in future get involvement in the process when they select the next person to move in. Certainly in the place that is supported living, like we are, it's only right that we get involved rather than get told who we're going to have. (p. 8)

In a study conducted by Beckwith, Friedman and Conroy on the leadership positions occupied by people with complex needs in disability specific organisations in the USA, the Beyond Tokenism study, they found that 25% of the people in leadership roles had developmental disabilities and approximately 5% complex needs (n= 2975 people in 160 organisations).<sup>188</sup> The authors reported that the supports most frequently provided and rated as important were:

- Accessible meeting space
- Financial assistance
- Having two or more individuals with complex needs on the board

Other supports frequently provided were board orientation and travel arrangements. Other supports rated as important although not frequently provided were adapting meeting procedures and leadership commitment to inclusion. When five or more people with complex needs had leadership roles in a given organisation, mentoring and pre-meetings were also relevant. The outcomes of having people with complex needs in leadership roles were:

- Increased leadership opportunities for the person

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<sup>187</sup> (Hoole & Morgan, 2011)

<sup>188</sup> (Beckwith et al., 2016b)



- Stronger relationships
- Expanded view of capabilities by others
- Increased inclusion
- Expanded influence with policymakers.

When organisations had 5 or more people in leadership roles, the impact also changed to having increased programme emphasis on community inclusion and expanded programme opportunities for people with disabilities.<sup>189</sup>

In short, to empower people with disabilities and their families to take control over their lives, the following strategies have been recommended:

- The person and the families are present for planning. Organisations acknowledge and act upon the person and families' decisions and implementation of plans are not dependent on the hierarchy of staff facilitating and implementing the plan
- Planning happens through informal environments and develops an attitude that acknowledges the person and/or family as the natural authority
- Families are involved in planning for persons with intellectual disability and dementia when changes in care occur and it is important to ensure a sense of continuity
- PCP is seen as a form of self-advocacy. The self-advocacy function is extended to assessment of services
- Members with intellectual disabilities are meaningfully included in partnerships and make the focus of the partnership a more inclusive society
- Boards of organisations include five or more people as representatives to change the focus towards more community inclusion
- Opportunities are provided for people to join self-advocacy groups, internal or external to the organisation, and for people to become more involved in services evaluation.

### **5.1.3. Working towards facilitating people with disabilities to say how they want to live their lives and what help, opportunities, and development of local capacities would make a contribution to change**

Self-advocacy training for people with intellectual disabilities has been identified as critical in enabling people to articulate the lives they want to have as part of the PCP process.<sup>190</sup> PCP, in turn, has been found to facilitate people to set goals. For example, Wigham et al. found that more participants had goals set post-PCP than prior to the implementation of the development of PCP in the areas of leisure, social networks, health, education, day services, material acquisitions, staff and support, vocational, and self-care.<sup>191</sup>

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<sup>189</sup> (Beckwith et al., 2016b)

<sup>190</sup> (Cambridge & Carnaby, 2005; García Iriarte, 2009; Walker, 2012)

<sup>191</sup> (Wigham et al., 2008)



Listening to people with intellectual disabilities is repeatedly mentioned in the literature as one of the key factors to successful PCP. For example, Parsons and colleagues state that for successful planning in community residences, staff should listen, acknowledge and trust what a person with a disability says. This should be complemented with the capacity to understand and accurately reflect the needs and aspirations of people with intellectual disabilities and consider which needs and aspirations are more important and need to be implemented more urgently, and to develop appropriate personalised strategies to address their needs and aspirations.<sup>192</sup>

Espiner and Hartnett found in their study that key elements for successful PCP were:

- Deep and ongoing listening to people with intellectual disabilities
- People with intellectual disabilities' understanding the plan
- People with intellectual disabilities' deeper involvement in the plan.<sup>193</sup>

In Espiner and Hartnett's study, plans were developed in scrapbook formats (including magazine pictures and written in plain English) and computer-generated formats (with text and pictures produced by staff). Another study on the participation of people with intellectual disabilities in the planning and evaluation of individual goals, found that key factors to successful participation in planning were:

- Training on human rights awareness
- Goal setting and choice making
- Preparation for the meeting
- Facilitation of the person's participation through the preparation, meeting and follow up stages of the planning process
- Accessibility of the information (for example, plain English text with pictures)
- Accessibility of the process (for example, all meeting participants used a picture-based meeting agenda developed and led by the person).<sup>194</sup>

Furthermore, PCP should include non-standard ways of communicating information when needed (pictures, signs, symbols, etc.).<sup>195</sup> Total communication<sup>196</sup> strategies have been recommended to facilitate people saying how they want to live their lives.<sup>197</sup>

Fyffe has also highlighted that decision making is often focused on simple decisions or in reaction to crisis and facilitators need to keep the decision making process

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<sup>192</sup> (Parsons et al., 2009)

<sup>193</sup> (Espiner & Hartnett, 2012)

<sup>194</sup> (García Iriarte, 2009)

<sup>195</sup> (Cambridge, 2008)

<sup>196</sup> Total communication is an approach that uses different combination of communication methods, verbal and non-verbal, to ensure successful communication with an individual. For example, total communication can involve body language, signing, photographs, drawings, and written words.

<sup>197</sup> (Taylor & Taylor, 2013)



relevant to the person who is the focus of the PCP.<sup>198</sup> Important aspects for review include:<sup>199</sup>

- The decisions that are taking more time and resources
- Whether decisions about resources take more time than decisions about addressing needs
- Whether family and friends are part of the decision-making process and if the meeting venue and time for making decisions allow the involvement of natural support
- Whether difficult and long-term decisions are discussed and made

However, PCP may not be appropriate to everyone, for example, people who have suffered abuse in the family or community.<sup>200</sup> PCP needs to be culturally valid and appropriate, responsive to gender, sexuality and age.<sup>201</sup> The appropriateness of PCP should be explored with the person.

In summary, PCP has the potential to give voice to people to set goals in areas that are of interest to them. This may be enhanced when people are trained in self-advocacy skills and PCP is seen as a form of self-advocacy. However, this requires listening to people and responding to their needs and aspirations. People with disabilities also need to understand the planning process. Factors contributing to enhanced understanding are training, facilitation and accessibility of information (for example, scrapbooks and picture-based information) and accessibility of the process (for example, the meeting agenda is a picture-based agenda already familiar to the person). Total communication can be employed to facilitate people say how they want to live their lives. Importantly, the decision making procedures in which people have their voices heard should be reviewed to focus on important decisions and not be reactive to crisis situations. PCP, however, may not be appropriate to everyone.

#### **5.1.4. Building a person centred culture and sustaining it**

There is consensus among researchers that PCP should be incorporated at all levels of the organisation and that organisations should avoid introducing PCP as a new service.<sup>202</sup> Robertson et al. found that a pre-existing person centred culture was positively associated with whether an individual would receive and benefit from PCP.<sup>203</sup> When PCP is incorporated as another service to meet the requirements (for example, to pass regulatory inspections), and it is connected to other services but does not underpin them, it is likely that it becomes a paper-based exercise.<sup>204</sup> In

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<sup>198</sup> (Fyffe, 2007)

<sup>199</sup> (Fyffe, 2007)

<sup>200</sup> (Cambridge, 2008)

<sup>201</sup> (Cambridge, 2008)

<sup>202</sup> (Cambridge & Carnaby, 2005; Dowling et al., 2007; Fitzsimons, 2012; Parsons et al., 2009; Robertson et al., 2007; Taylor & Taylor, 2013; Walker, 2012)

<sup>203</sup> (Robertson et al., 2007)

<sup>204</sup> (Cambridge & Carnaby, 2005; Dowling et al., 2007; Parsons et al., 2009; Robertson et al., 2007; Taylor & Taylor, 2013)



Fitzsimons words, “it is diminished to a bureaucratic, soulless and mandatory process” (p. 273).<sup>205</sup> Dowling and colleagues conclude from their review of the literature that organisations are more likely to support PCP if they embrace a service culture that promotes empowerment and inclusion as core values, that is open to possibilities and that takes risks, in short, a service culture that “thinks outside traditional planning models” (p. 79).<sup>206</sup>

Dowling and colleagues signal that person-centred service cultures should have the core values of inclusion and self-determination and endeavour to give power to service users.<sup>207</sup> Some of the proposals to share power with individuals and their families involve developing the capacity of staff through:<sup>208</sup>

- Training
- Decentralisation of resources and responsibilities
- Horizontal management
- Accessible communication
- Advocacy.

Changing organisational cultures, however, remains one of the main challenges to implementing PCP. As Ratti and colleagues mention in their review, changing an organisational culture to a PCP culture may be more difficult when services have established practices in place and therefore may be more resistant to change.<sup>209</sup> Supporting this conclusion, Thompson and colleagues argue that individualised support provision is difficult in itself but it is even more difficult when organisations are not aligned to this support paradigm.<sup>210</sup> Black goes even further to suggest that new services may be developed to implement PCP rather than existing services transformed.<sup>211</sup>

The Seeing is Believing initiative offers an example to promote organisational change in the area of individualised support provision to people with intellectual disabilities.<sup>212</sup> The example is illustrative of how PCP is targeted along with training, organisational strategic planning, and connections with the community and the State. This initiative was developed in North Carolina with the aim to promote organisational change within provider organisations to enable them to shift towards supported living and the inclusion of persons with intellectual disabilities in the community through the provision of individualised supports. The strategies used in the project are presented in Table 5.1.

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<sup>205</sup> (Fitzsimons, 2012)

<sup>206</sup> (Dowling et al., 2007)

<sup>207</sup> (Dowling et al., 2007)

<sup>208</sup> (Cambridge, 2008)

<sup>209</sup> (Ratti et al., 2016)

<sup>210</sup> (Thompson, Schalock, Agosta, Teninty, & Fortune, 2014)

<sup>211</sup> (Black, McConkey, Roberts, & Ferguson, 2010)

<sup>212</sup> (Walker, 2012)



**Table 5.1. “Seeing is Believing” strategies**

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<ul style="list-style-type: none"><li>• Training and technical assistance</li></ul>	<ul style="list-style-type: none"><li>• Training on PCP</li><li>• Organisational planning</li><li>• Designing individualised supports for the organisation<ul style="list-style-type: none"><li>○ Organisational plans for change across staff, managers and board members</li><li>○ Revise organisational policies and procedures</li><li>○ Develop and implement individual PCP</li><li>○ Train staff in PCP and in the provision of individualised support that promote self-determination, community inclusion and social relationships</li><li>○ Assist individuals with disabilities to become involved in self-advocacy</li><li>○ Training for persons and their families about individualised supports, expectations for the planning process, self-advocacy and funding strategies</li><li>○ Learn about the use of community housing including issues with loans, mortgages, etc.</li><li>○ Develop true collaboration with other stakeholders in both the public and private sectors to allow flexible rules and funding</li><li>○ Develop a train the trainer approach</li></ul></li></ul>
<ul style="list-style-type: none"><li>• Technical assistance from other national consultants, for example, to develop micro-enterprises and to develop community connections</li><li>• Creating a learning community for the agencies involved in the initiative</li><li>• Reaching broader audiences through training and conferences</li><li>• Partnerships and collaboration with the state such as self-advocacy organisations and the Money Follows the Person initiative</li><li>• Promoting dialogue with state agencies regarding individualised supports, the focus of the conversation being “How can we be more flexible in how we support people that will at the same time meet the desired objectives identified by the state?”</li></ul>	

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Source: Walker (2012)

Walker concluded that organisational change is about strengthening the culture of organisations and building community supports. She acknowledged, however, that this is complex and requires long term efforts.<sup>213</sup>

In an evaluation study conducted in Ireland by McConkey, Bunting, Ferry, García Iriarte and Stevens on the provision of individualised support to people moving to community accommodation, one of the findings indicated that the central driver for change was the service organisation which had undertaken a cultural shift from dependency to empowerment.<sup>214</sup> This cultural shift was accompanied by the development of an explicit policy for individualised support that involved:

- The vision for the new form of service delivery
- Active leadership promoting the new policy throughout the organisation and with other stakeholders

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<sup>213</sup> (Walker, 2012)

<sup>214</sup> (McConkey, Bunting, Ferry, Garcia Iriarte, & Stevens, 2013)



- A team of persons implementing the policy that were separate from the day-to-day operations and delegating authority to them
- A co-ordinator to oversee and manage the process
- Learning throughout the process.

In short, the findings in relation to strengthening the PCP organisational culture include:

- PCP should be incorporated at all levels of the organisation rather than incorporating it as a new service. Service organisations with person-centred cultures have been found to be associated with more individuals receiving plans and more benefiting from them
- Organisations are more likely to embrace PCP if they have a culture of empowerment and inclusion as their core values and if they are flexible to collaborate with other service providers
- Organisational change is difficult. An organisational systems change intervention conducted in North Carolina targeted PCP along with training, organisational strategic planning and the connections between the organisation and the State
- In a study conducted in Ireland on the provision of individualised support to people to move to community living, the findings indicate that the central driver of change was the organisational culture shift from dependency to empowerment.

#### **5.1.5. Working more generally on developing an overall climate that is supportive of people with disabilities becoming fully part of, benefiting from and making contributions to their local communities**

Espiner and Hartnett found that successful PCP was dependent on the flexibility of organisations to work with other services and apply community-building approaches.<sup>215</sup> This finding resonates with Robertson and Emerson's study that identified the important role of organisations and case managers advocating beyond the organisations where they work for improving employment opportunities and self-determination of people with intellectual disabilities.<sup>216</sup>

The work around the contribution of people to their local communities is also reflected in the increasing call for support staff to become community connectors rather than skills developers.<sup>217</sup> One example from the literature on employment provides evidence of how this may be achieved. In a study by Carter and colleagues on summer placements for students with intellectual disabilities, they used "community conversations" to involve the community in thinking about what the community in general, and individuals in particular, could do to help people to gain and maintain employment.<sup>218</sup> They also used "resource mapping" to gather all the

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<sup>215</sup> (Espiner & Hartnett, 2012)

<sup>216</sup> (Robertson & Emmerson, 2007)

<sup>217</sup> (Gomez, 2013)

<sup>218</sup> (Carter et al., 2009)



information about resources in the local community. The study used an employer liaison, who was an employer, to connect the person in search of employment with potential employers.<sup>219</sup>

In summary, organisations have a role advocating for wider systems change to improve opportunities for engagement with the community and self-determination of people with disabilities and they should involve the community in these efforts.

## **5.2. Clarifying roles and responsibilities**

PCP should bring together the person who is the focus of PCP, paid support and natural support. Parsons et al. reported that factors associated with successful outcomes for people in residential services included personal involvement of the individual and a person-centred team.<sup>220</sup> In another study, conducted by McCarron et al., key enabling factors included staff and organisational support for PCP, family and multi-disciplinary involvement, and a service culture promoting PCP.<sup>221</sup>

The following stakeholders have been identified as playing key roles in PCP:

- The person who is the focus of the PCP
- Staff implementing PCP
- PCP facilitators
- Natural support including the family

### **5.2.1. The person who is the focus of the PCP**

The person has a central role and it should be imperative for them to be part of the planning.<sup>222</sup> The role of the person is to communicate their needs, wishes and preferences, make decisions about the planning process, and about their plans, and make choices about the support to participate in the meetings and to implement and evaluate the plan.<sup>223</sup> Towers and Wilkinson signal the same role in PCP for people with intellectual disabilities and dementia.<sup>224</sup> For example, strategies recommended by Towers and Wilkinson to involve people with intellectual disability and dementia in decision making are:

- Supporting people to be involved and to take the lead (for example, through choosing where, when, and with whom the planning should take place)
- Talking to people in first person and involving them in the discussion
- Having discussions at an adequate pace, giving people space, and supporting them to communicate

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<sup>219</sup> (Carter et al., 2009)

<sup>220</sup> (Parsons et al., 2009)

<sup>221</sup> (McCarron et al., 2013)

<sup>222</sup> (Cambridge & Carnaby, 2005)

<sup>223</sup> (Bigby et al., 2007; Cambridge, 2008; Parsons et al., 2009)

<sup>224</sup> (Towers & Wilkinson, 2014)





- Using individualised communication support such as drawings, pictures, objects, photographs, etc..<sup>225</sup>

In the study conducted by Friedman, Beckwith and Conroy, the following strategies were used for people with communication needs and for people with attention support needs: <sup>226</sup>

- For people with communication needs: communication devices and a staff person or a personal care assistant who provided interpretation
- For people with attention support needs: breaks, additional meeting room available, giving earphones to stay focused, timekeepers and training on how to respond to service animals during meetings
- Organisations with three or more people with complex needs also used informal meetings with smaller discussion groups, training for all members of the organisation on how to listen to people with intellectual disabilities, pre-meetings, reimbursement of expenses and involvement of people with intellectual disabilities in other internal and external organisational activities (besides the board) (for example, as reviewers of funded projects, in advocacy, and legislative affairs).

In a study conducted by Espiner and Hartnett, participants felt able to share wishes, which others had not previously known and felt that support to develop their communication skills was important to enhance their role at the meeting.<sup>227</sup>

Beckwith and colleagues identified in a literature review that a number of elements should be in place for the successful inclusion of people with intellectual disabilities in leadership roles (the study focused on leadership roles in organisational boards) and to have an impact in both individual and organisational outcomes (see Table 5.2). <sup>228</sup> These elements can be applied to PCP participation given that the person should have a leading role in the plan.

**Table 5.2. Elements of Board Inclusion**

Authentic membership	Indicators of equal status to, and recognition of, the presence of the individual to be as important as any other member of the board of directors
Deliberate communication	Indicators that the ways the individual receives, processes, and expresses information and ideas are accommodated with regard to content and processes
Full participation	Indicators that the interests and preferences of the individual are used to establish ongoing involvement with board functions and activities
Meaningful contributions	Indicators that the gifts, talents, and experience of the individual are used in ways that expand their responsibilities

<sup>225</sup> (Towers & Wilkinson, 2014)

<sup>226</sup> (Friedman, Beckwith, & Conroy, 2016a)

<sup>227</sup> (Espiner & Hartnett, 2012)

<sup>228</sup> (Beckwith et al., 2016a)



	as board members
True influence	Indicators that the ideas or concerns expressed by the individual are acknowledged and acted on
Transformational outcome: individual	Authentic acceptance of the individual in which the person's functional and social contributions are integrated into the board's activities
Transformational outcome: organisational	Authentic social acceptance of diverse board members, as well as functional inclusion in issues, processes, and decisions made by the board.

Source: Beckwith et al. (2016)

Friedman and colleagues also found that organisations were very effective at providing supports for functional inclusion (organisational strategies for the inclusion of diverse members in their boards) and social inclusion (participation in the social fabric of the board based on meaningful relational connections). However, fewer comments were made by participants about transformational inclusion, the end goal of inclusion (authentic exchanges between board members and an altered culture).<sup>229</sup>

Strategies used to empower individuals with intellectual disabilities in their boards were used not only for them but for the wider membership.<sup>230</sup> For example, making documents easier to read benefitted the larger board. However, the provision of this support requires a cultural shift. One of the main challenges found by the authors of the study was the provision of user-friendly, easy-to-read materials.

### 5.2.2. Staff implementing PCP

Fitzsimons identifies two types of roles played by staff in relation to PCP, key workers (facilitate the plan) and other staff (implement the plan).<sup>231</sup> This section deals with staff who help implement the plan while section 5.2.3 (plan facilitators) focuses on the role of facilitators. In this section, we review the role of support staff as enablers of goal accomplishment and their training needs.

#### 5.2.2.1. Support staff as enablers of goal accomplishment

Support staff have been found to be one of the most powerful enablers of goal accomplishment.<sup>232</sup> For example, in the study by McConkey and Collins, the following factors were identified as enablers of goal accomplishment: staff assisting with arranging or booking activities and accompanying the individual.<sup>233</sup> Resonating with the above example, Espiner and Hartnett found that participants were keen to widen their social networks and had suggested ways in which this might be achieved. However, poor or no attendance by some professionals meant many goals could not

<sup>229</sup> (Friedman, Beckwith, & Conroy, 2016b)

<sup>230</sup> (Friedman et al., 2016b)

<sup>231</sup> (Fitzsimons, 2012)

<sup>232</sup> (Claes et al., 2012; Fitzsimons, 2012; García Iriarte, 2009; McCarron et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006)

<sup>233</sup> (McConkey & Collins, 2010)



be implemented.<sup>234</sup> In a study by Sheerin and colleagues, customised staff support was seen by all as hugely important with respect to increasing independence and providing social and emotional security.<sup>235</sup>

#### 5.2.2.2. Training needs of support staff

Windley and Chapman conducted a study to understand the perceptions of 8 support workers working with adults with intellectual disabilities, their training and support needs in a joint health and social care service.<sup>236</sup> The study suggested that supervision did not guarantee support workers' ability to meet quality standards nor how they related to PCP. They also identified that programme activities and information had to be written and accessible and joint working was successful. Staff implementing the plan need to engage at the stage when the plan is being developed, rather than staff implementing interventions which they had not planned. More supervision and modelling of good practice by senior staff and the organisation of staff time could lead to improvements in service quality.<sup>237</sup>

McCarron et al. confirm the need for reviewing staff's beliefs about the person they support, specifically:<sup>238</sup>

(staff's) belief in the potential for an individual service user to be more independent and willingness to think in non-traditional ways about how to support the dreams and goals of service users (p. 13).

The authors suggest addressing these through training and the opportunity to experience new ways to meet needs.<sup>239</sup>

Implementing PCP, however, does not necessarily imply that new staff need to be hired. In the study conducted by Robertson and colleagues in the UK in 2005, the authors recommend to see PCP as a transformative and "positive step in delivering individualised support to enhance the quality of life of people with intellectual disabilities" (p. 413).<sup>240</sup> This recommendation resonates with others who point to the need to re-train competent staff into new support models.<sup>241</sup> The idea of re-training staff links to the need for continuity of relationships and a depth of knowledge of the person.<sup>242</sup> Parsons and colleagues, for example, have noted the risk, when people move houses, and have to develop relationships with new staff. In one example they

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<sup>234</sup> (Espiner & Hartnett, 2012)

<sup>235</sup> (Sheerin et al., 2015)

<sup>236</sup> (Windley & Chapman, 2010)

<sup>237</sup> (Windley & Chapman, 2010)

<sup>238</sup> (McCarron et al., 2013)

<sup>239</sup> (McCarron et al., 2013)

<sup>240</sup> (Robertson et al., 2006)

<sup>241</sup> (García Iriarte et al., 2016; Walker, 2012; Windley & Chapman, 2010)

<sup>242</sup> (Cambridge & Carnaby, 2005)



provide, planning occurred when there was no-one who had known the person for more than three months.<sup>243</sup>

A study conducted by the Inclusive Research Network in Ireland identified that people with intellectual disabilities looked for paid staff who were friendly and with a sense of humour, respectful, agreeable and punctual, good listeners, good planners, supportive of people getting out when they want and helpful with decision making.<sup>244</sup> Researchers have highlighted the role of support staff in connecting the person to the community, through financial resources and staff with the skills to facilitate relationships.<sup>245</sup> Campanella also suggests that the role of support staff is closer to the role of a coach who helps the person make decisions through questions and reflection in day to day interactions that support choice and decision making.<sup>246</sup>

To summarise, support staff are one of the most powerful enablers of goal accomplishment and a lack of staff often leads to unmet goals. The involvement of paid staff in planning has been recommended to facilitate PCP implementation. Implementing PCP does not require hiring new staff, as people can be re-trained in new support models, which can enable long term relationships between staff and service users and a deep knowledge of the person. Lastly, people with intellectual disabilities have clear preferences for the characteristics of support staff. This role should be oriented towards facilitating community inclusion.

### **5.2.3. PCP facilitators**

The importance of facilitators in PCP cannot be over-stated. In the study conducted by Robertson and colleagues, facilitators were identified as the strongest predictor for people of getting a plan.<sup>247</sup>

In Robertson et al.'s study, findings indicate that facilitators for whom facilitation was recognised as part of their formal job role were more likely to deliver plans and the persons they facilitated more likely to benefit in relation to the size of their social network and number of hours of scheduled activities. For those facilitators who are members of management staff, the persons they facilitated benefited more in the areas of size of social networks, community activities and choice. Having a facilitator member of support staff (rather than managers) was associated with larger social networks but with less community activities, less contact with friends and less contact with family.<sup>248</sup> Kaehne and Beyer also concur on the importance of

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<sup>243</sup> (Parsons et al., 2009)

<sup>244</sup> (Inclusive Research Network, 2015)

<sup>245</sup> (Power, 2013; Taylor & Taylor, 2013; Walker, 2012)

<sup>246</sup> (Campanella, 2015)

<sup>247</sup> (Robertson et al., 2006)

<sup>248</sup> (Robertson et al., 2007)



facilitators to increase the participation of youth with disabilities in the PCP meeting and to focus the discussion.<sup>249</sup>

In Ireland, key workers are responsible for developing PCP. Staff can be the key worker of one person (facilitate their plan) while they also support other persons with intellectual disabilities (implement their plan). Fitzsimons found that key workers have a conflict of interest meeting the support needs of residents in their care and having a specific role in relation to the person for whom they are a key worker.<sup>250</sup> Key workers demonstrated difficulty in advocating for a positive future for the person who is the focus of the PCP when they saw PCP as a bureaucratic and mandatory exercise. As shown by Fitzsimons in his study, the personal goals of people for whom they were facilitators were secondary to the established routine in the residential setting.<sup>251</sup>

Key workers also have a dual role of facilitating the person with intellectual disability with their personal goals while they also have to report to their line managers.<sup>252</sup> Staff who had a higher position in the hierarchy of the organisation had more decision making power to implement goals while staff in a lower rank had to adhere to the routine.

There is a clear indication in the literature that the role of case managers, which is identifying services to meet the needs of individuals, should be underpinned by person centredness but should not involve the facilitation of PCP in order to ensure independence from service organisations.<sup>253</sup> However, independence from services may involve practical difficulties as in a study by Xie, Hughes, Challis, Stewart and Cambridge, they found that a significant number of respondents confirmed that case managers were responsible for PCP.<sup>254</sup> In another study conducted by Espiner and Hartnett, the role of a new facilitator was created and staff were appointed as facilitators, although not independent from the organisation, to minimise conflicts of interest and provide greater autonomy.<sup>255</sup> Previously within the organisation, direct service staff had undertaken the facilitation of PCP. Although in this study the role of facilitator provided a greater degree of autonomy, it was not entirely independent from the organisation. The authors recommend as a next step exploring ways of planning that are independently facilitated rather than service-led.

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<sup>249</sup> (Kaehne & Beyer, 2014)

<sup>250</sup> (Fitzsimons, 2012)

<sup>251</sup> (Fitzsimons, 2012)

<sup>252</sup> (Fitzsimons, 2012)

<sup>253</sup> (Cambridge, 2008; Xie et al., 2008)

<sup>254</sup> (Xie et al., 2008)

<sup>255</sup> (Espiner & Hartnett, 2012)



In the study conducted by Friedman et al. the role of the mentor to support people with complex needs in leadership roles, and which were different from care attendants' tasks, involved:<sup>256</sup>

- “Reviewing the agenda and meeting materials prior to the meeting
- Serving as a go-to person to address issues as needed
- Assisting with arranging transportation
- Attending pre-meetings and meetings
- Explaining items or providing other assistance at the meetings as needed” (p. 178).

The role of professionals, however, is unclear as the PCP process is supposed to be driven by the person.<sup>257</sup> The role of professionals, persons and their families is disputed, as on one side it would be unrealistic for people who do not have experience making decisions about services to take the lead.<sup>258</sup> On the other side, organisations need to be very clear about valuing professionals taking on this role and training them.<sup>259</sup> Recommendations from the transition literature reviewed point at the need for facilitators to develop a relationship with the person before they engage in PCP meetings and that they are available throughout the process, before the planning, during, and at the follow up stage.<sup>260</sup>

Furthermore, Robertson et al. indicate that the underlying advocacy values of facilitators from a Citizen Advocacy Service appeared to be a strong factor in achieving change with people.<sup>261</sup> This finding resonates with García Iriarte, Stockdale, McConkey and Keogh, who found that training provided to staff on community support contributed to viewing people with intellectual disabilities as having the same rights as others and therefore, it facilitated the transition of people with intellectual disabilities to community living.<sup>262</sup> This is relevant in light of McConkey and colleagues' findings who reported that people who lived with their families or in personalised living arrangements had greater choice of support worker (compared to people living in group homes and residential institutions).<sup>263</sup> The latter suggests that people living in group homes and residential institutions may have fewer options to choose facilitators with advocacy values. Towers and Wilkinson suggest that money from individualised budgets can be used for hiring facilitators.<sup>264</sup>

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<sup>256</sup> (Friedman et al., 2016a)

<sup>257</sup> (Taylor & Taylor, 2013)

<sup>258</sup> (Coyle, 2007)

<sup>259</sup> (Cambridge, 2008; Xie et al., 2008)

<sup>260</sup> (Hagner et al., 2012; Hagner et al., 2014; Wehmeyer et al., 2006)

<sup>261</sup> (Robertson et al., 2006)

<sup>262</sup> (García Iriarte et al., 2016)

<sup>263</sup> (McConkey et al., 2013)

<sup>264</sup> (Towers & Wilkinson, 2014)



In summary, the literature reviewed highlights that PCP depends on the availability of facilitators who are committed to PCP.<sup>265</sup> Facilitators who have facilitation recognised as part of their formal job have been found to be more likely to provide plans and for people with intellectual disabilities to benefit from them.<sup>266</sup> Facilitators who are part of management staff are associated with more benefits resulting from the plan than facilitators who are part of direct service staff.<sup>267</sup> Cambridge and Xie strongly advise that facilitators should ensure their own independence from services.<sup>268</sup> However, this is more difficult to implement in practice.<sup>269</sup> Facilitators with underlying advocacy values and trained in community inclusion are more likely to influence changes in people's lives such as community inclusion.<sup>270</sup>

#### **5.2.4. Natural support**

A common characteristic of PCP is the involvement of a network of informal support working along with services.<sup>271</sup> For people who find it difficult to communicate their needs, it is even more important that they find advocates or other people who can speak up for them.<sup>272</sup> Towers and Wilkinson recommend having a number of people involved.<sup>273</sup> The role and autonomy of the family is central to PCP as they would know the person best.<sup>274</sup> Some authors have cautioned, however, that the family can become over-involved and that there is a risk that they may misrepresent their relatives' preferences if they speak for them.<sup>275</sup> Or simply that people with intellectual disabilities' wishes conflict with those of their family members.<sup>276</sup>

Heller and Schindler identified several projects/organisations that aim to support older carers<sup>277</sup> (for example, Sharing Caring Project 2008, Carers FIRST 2008, Aging with Developmental Disabilities Family Future Planning Project 2006). The authors conclude that there is evidence of the value of consumer directed family supports and the benefits of helping families to make future plans but the research base is weak.<sup>278</sup> Heller and Kramer surveyed 139 adult siblings of a person with a developmental disability to explore future planning activities and plans. The findings

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<sup>265</sup> (Dowling et al., 2007; Parsons et al., 2009; Robertson et al., 2007)

<sup>266</sup> (Robertson et al., 2006)

<sup>267</sup> (Robertson et al., 2006)

<sup>268</sup> (Cambridge, 2008; Xie et al., 2008)

<sup>269</sup> (Xie et al., 2008)

<sup>270</sup> (Robertson et al., 2006)

<sup>271</sup> (Cambridge, 2008)

<sup>272</sup> (Parsons et al., 2009)

<sup>273</sup> (Towers & Wilkinson, 2014)

<sup>274</sup> (Cocks et al., 2009; Parsons et al., 2009; Towers & Wilkinson, 2014)

<sup>275</sup> (Taylor & Taylor, 2013; Van Ingen et al., 2008)

<sup>276</sup> (Genio, 2014)

<sup>277</sup> The term carers is used in this report as it is used in the articles cited to refer to family and non-family members providing care and support to people with intellectual disabilities.

<sup>278</sup> (Heller et al., 2011)



of the study suggest that few families had plans and siblings were not generally involved in the planning although more than a third of participants expected to become the main caregiver for their relative. The study indicates that the siblings' support needs included support groups, caregiving training, economic support and printed information on how to plan.<sup>279</sup>

A network of support that consists of unpaid people is very important especially if parents are old or family does not live nearby.<sup>280</sup> However, Taylor and Taylor caution against making plans only dependent on natural supports as this may prevent people from receiving more resources. Furthermore, Taylor and Taylor emphasise the importance of being aware of resources as plans may have “legitimate limitations” (p. 229).<sup>281</sup> One of the most burgeoning strategies to develop informal support for people with intellectual disabilities are circles of support.<sup>282</sup>

#### 5.2.4.1. Circles of support

A circle of support involves a group of friends, family, and sometimes, staff coming together to support an individual, assisting them to identify things they would like to achieve or alter in their life and then putting in place supports to make this happen.<sup>283</sup> As such, circles of support can be envisaged either as a form of PCP or as part of the PCP process.<sup>284</sup> Advocates see it as a powerful means of empowering disabled people to actively partake in decisions about their lives.<sup>285</sup>

Clark, Garland and Williams argue that people with intellectual disabilities can expand their support network, which is beneficial not only for the person but to all involved.<sup>286</sup> This resonates with Towers and Wilkinson.<sup>287</sup> According to Clark and colleagues, professionals can also play a role in circles of support by acting as volunteers (because they really care about the person) or by working in their professional role to establish formal communication with the circle.<sup>288</sup> Informal supports need to connect people to wider self-advocacy groups independent from service organisations.<sup>289</sup>

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<sup>279</sup> (Heller & Schindler, 2009)

<sup>280</sup> (Towers & Wilkinson, 2014)

<sup>281</sup> (Taylor & Taylor, 2013)

<sup>282</sup> (Franklin & Sanderson, 2014)

<sup>283</sup> (Wistow et al., 2016)

<sup>284</sup> (Wistow et al., 2016)

<sup>285</sup> (Wistow et al., 2016)

<sup>286</sup> (Clark et al., 2005)

<sup>287</sup> (Towers & Wilkinson, 2014)

<sup>288</sup> (Clark et al., 2005)

<sup>289</sup> (Walker, 2012)





Circles of support should meet regularly, contribute to PCP and make sure the necessary approaches are put in place to accomplish people's goals.<sup>290</sup> According to Towers and Wilkinson:

- Families can become part of the circles of support of other people they know
- Circle facilitators can be paid through personal budgets
- Circles can help develop friendship and a sense of security for all circle members
- Members can:
  - Share stories of the past with the person
  - Plan important changes (for example, a move to a new house)
  - Have a role as advocates, trustees or executors
  - Monitor plan implementation and goal accomplishment.

Hillman and colleagues found that the rights of persons with intellectual disabilities were over-ridden by service providers and that their family members experienced vulnerability to having their rights violated.<sup>291</sup> The strategies used by the networks of support to ensure people with disabilities' rights were respected included:

- Deeply knowing the person being supported
- Involving a wider range of people
- Promoting the person's autonomy
- Building capacity among network members
- Developing choice making skills
- Having people with intellectual disabilities at the centre of all discussions.

However, people with intellectual disabilities often have a very small network of contacts, including mostly family members and paid staff and this is even more pronounced for older adults with intellectual disabilities.<sup>292</sup> Cambridge and Carnaby challenge us to think about whose responsibility is it to develop these networks in an overall context of social exclusion.<sup>293</sup> Coupled with social exclusion, limited resources often limit efforts for active participation of people with intellectual disabilities in their communities.<sup>294</sup> If planning is introduced when there are no family members available, Parsons and colleagues recommend addressing the lack of social networks as part of the PCP process and making it a priority.<sup>295</sup> The importance of staff who can support individuals to build community connections becomes even

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<sup>290</sup> (Towers & Wilkinson, 2014)

<sup>291</sup> (Hillman et al., 2012)

<sup>292</sup> (Cambridge & Carnaby, 2005; Taylor & Taylor, 2013)

<sup>293</sup> (Cambridge & Carnaby, 2005)

<sup>294</sup> (García Iriarte et al., 2016; Taylor & Taylor, 2013)

<sup>295</sup> (Parsons et al., 2009)



more crucial here.<sup>296</sup> Towers and Wilkinson add that planning should start early and not be led by emergency situations.<sup>297</sup>

In all, a mix of support, including formal and informal has been found to help people accomplish outcomes. For example, McConkey and Collins reported that having friends to go places with, having in-house staff supporters, having family support and having own transport contributed to goal accomplishment in the area of community inclusion.<sup>298</sup> However, responsibility over the plan is a critical factor identified in the literature. For example, in their review of evaluative research of lifestyle planning, Robertson and Emerson identified that the lack of responsibility in plans had led to unmet goals.<sup>299</sup> The responsibilities vary along a continuum where on one end the professional is responsible for PCP and works in collaboration with the person and the family and on the other end, the person and the family manage the plan and resources.

To summarise, the involvement of informal support is a common characteristic of PCP. There is evidence, although weak, of the benefits of involving family in future planning. Siblings are not generally involved in the planning although they are likely to become primary carers in the future. One of the strategies used to involve informal support in planning is through circles of support, including family, friends, and other people with disabilities. However, people with intellectual disabilities often lack a network of support. If this is the case, developing social relationships should be addressed as part of PCP.

### **5.3. Identifying training and support that will be required**

In the literature reviewed, training has been identified as a core component of PCP implementation. The adoption of PCP should happen at an organisational level, and therefore, training has been recommended for people with disabilities who are developing their PCP, plan facilitators, staff implementing plans, and families or other informal support. Other members of the organisation not directly involved in the planning should also be knowledgeable of PCP. Training on the values base of PCP to all stakeholders in the organisation has been identified as critical to the adoption of a PCP culture.<sup>300</sup>

#### **5.3.1. The person who is the focus of the PCP**

To successfully participate in PCP, the literature has identified that persons with disabilities need training in a number of areas, including self-advocacy, making

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<sup>296</sup> (García Iriarte et al., 2016; McConkey et al., 2013; Parsons et al., 2009; Power, 2013; Walker, 2012)

<sup>297</sup> (Towers & Wilkinson, 2014)

<sup>298</sup> (McConkey & Collins, 2010)

<sup>299</sup> (Robertson & Emerson, 2007)

<sup>300</sup> (Walker, 2012)



decisions, funding options, and communication skills.<sup>301</sup> For people with intellectual disabilities, training on self-advocacy has been recognised as critical to enable them to articulate the lives they want to have as part of the PCP process.<sup>302</sup> In a study conducted by McConkey and colleagues, access to training in advocacy was more likely to happen for people who lived with their families compared to those living in residential institutions or group homes.<sup>303</sup> Their findings suggest that training in advocacy preceded moves to personalised arrangements.<sup>304</sup>

Furthermore, training on decision-making and building social capital for people with intellectual disabilities has been acknowledged as key to their empowerment.<sup>305</sup> In an intervention to facilitate people with intellectual disabilities' participation in the planning of their services, the training focused on rights' awareness, goal setting and choice making.<sup>306</sup> The results of the intervention suggested that the intervention group was able to identify their preferences and set goals following the training, which did not occur before the training or for their peers in the comparison group.

In transition programmes, PCP training has been documented as one of the core components, often provided along with other strategies, such as interagency collaboration. PCP training in transition generally involves:

- Goal setting
- Choice making and decision making
- Self-determination
- Communication skills
- Identifying people's wishes and preferences.<sup>307</sup>

### 5.3.2. Staff implementing PCP

Staff implementing PCP should also be trained on PCP. Through the literature, the following have been identified as training areas for staff implementing the plans: PCP and human rights, active support, and communication. Windley and Chapman suggested, based on the findings of their study, that human rights training in combination with PCP would be more effective to implement PCP for staff working in residential facilities and, in turn, it would provide staff with a better understanding about their role.<sup>308</sup> They also stated that human rights training would be more facilitative of an advocacy function. The findings of their study suggest that PCP

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<sup>301</sup> (Espiner & Hartnett, 2012; García Iriarte, In press; Taylor & Taylor, 2013; Towers & Wilkinson, 2014)

<sup>302</sup> (Cambridge & Carnaby, 2005; García Iriarte, 2009; Taylor & Taylor, 2013; Walker, 2012)

<sup>303</sup> (McConkey et al., 2013)

<sup>304</sup> (McConkey et al., 2013)

<sup>305</sup> (Walker, 2012)

<sup>306</sup> (García Iriarte, In press)

<sup>307</sup> (Hagner et al., 2014; Wehmeyer et al., 2006; Wehmeyer et al., 2009; Yamamoto, Stodden, & Folk, 2014)

<sup>308</sup> (Windley & Chapman, 2010)



training resulted in a more positive atmosphere in the residential house.<sup>309</sup> Walker also notes the need to train staff in PCP and in the provision of individualised support that promotes self-determination, community inclusion and social relationships.<sup>310</sup>

Williams, Ponting, Ford and Rudge state that training for supporters needs to be customised to the individual.<sup>311</sup> They identify in their study the following general guidelines for successful communication between staff and people with intellectual disabilities: stepping back, talking in an adult tone of voice, and following the lead of the person with intellectual disabilities.<sup>312</sup>

The five themes underpinning good support involve respect, choices, friendliness, giving advice and support to speak up. Showing respect is done by letting the person take the lead and offering support when requested, and providing the opportunities for taking turns when talking. Good personal assistants are very alert to provide support when people can make choices. The role of personal assistants is to provide advice while empowering the person and ensuring safety. They approach their work by giving priority to the perspective of the person supported and using various strategies (see table 5.3).

**Table 5.3. Support strategies for personal assistants**

Stepping back	Redressing the balance of power between the person with intellectual disabilities and staff
Listening and observing	Personal assistants often need to remind people to make choices, listening and responding to things that are not part of the plan and using an adult tone of voice
Body language	Mutual smiling and laughter, following the body language of the person being supported, staying in tune
Time	Whose agenda is it?, the person is responsible for what gets done and what does not
Team work	Discussing with the person
Personal knowledge	Get to know the person, close relationship which includes experiences and activities
Putting it all together	What to do next and what needs to be done, planning ahead, reacting appropriately to emergencies and unexpected events

Source: Williams et al. (2010)

Training on active support (micro-planning the person's activities and providing support on a daily basis) for staff working in residential services for people with intellectual disabilities has been found to be facilitative of PCP.<sup>313</sup> The study by Rhodes and Hamilton found that following training in active support, staff portrayed residents in a positive light, with a focus on their strengths and skills.<sup>314</sup> Staff were more

<sup>309</sup> (Windley & Chapman, 2010)

<sup>310</sup> (Walker, 2012)

<sup>311</sup> (Williams et al., 2010)

<sup>312</sup> (Williams et al., 2010)

<sup>313</sup> (Rhodes & Hamilton, 2006)

<sup>314</sup> (Rhodes & Hamilton, 2006)



satisfied with their jobs following training. They were focusing on residents and getting on with supporting people more efficiently. Staff participating in the study described a positive atmosphere in the house. A significant part of the training provided was one-to-one and involved role modelling by project officers where they showed how active support should be provided.

Evidence on the effect of person-centred active support on service users' outcomes, however, provides conflicting findings. Mansell, Beadle-Brown, Whelton, Beckett, and Hutchinson found that there was no difference in choice-making between a group that had received a person-centred active support intervention and a control group.<sup>315</sup> These findings contrast with those from a study conducted by Beadle-Brown, Hutchinson and Whelton and a study by Rhodes and Hamilton, who found that person centred active support increased the provision and quality of support and this, in turn, led to an increase in service-users opportunities for engagement, participation and choice-making.<sup>316</sup> Rhodes and Hamilton reported increases in service users' engagement in activities from baseline to post-training, challenging behaviour increased at post-training but decreased after training had been provided, and residents' quality of life improved significantly after the training.<sup>317</sup>

### **5.3.3. PCP facilitators**

Taylor and Taylor identify training as one of the main barriers to demonstrating the effectiveness of PCP.<sup>318</sup> The authors recommend that agencies should be responsible for monitoring staff training and only people with significant experience in PCP should be responsible for implementing it.<sup>319</sup>

Training for key workers and facilitators of PCP has been recommended, including the following areas: context for PCP and implementation strategies such as communication supports. In Robertson et al.'s study, a central aim of the development phase was the training of facilitators.<sup>320</sup> The training focused on theoretical aspects such as principles and values, history and policy of PCP, and on practical features including communication, health action planning and planning tools. The training provided in Espiner and Hartnett's study to facilitators also included a theoretical approach to PCP (values, the PCP process) and practical aspects of PCP, such as communication skills.<sup>321</sup> The authors emphasised the centrality of listening as well as accessible communication formats. Other aspects of the training included: problem solving, group dynamics, networking and identifying community resources.<sup>322</sup>

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<sup>315</sup> (Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008)

<sup>316</sup> (Beadle-Brown, Hutchinson, & Whelton, 2012)

<sup>317</sup> (Rhodes & Hamilton, 2006)

<sup>318</sup> (Taylor & Taylor, 2013)

<sup>319</sup> (Taylor & Taylor, 2013)

<sup>320</sup> (Robertson et al., 2005)

<sup>321</sup> (Espiner & Hartnett, 2012)

<sup>322</sup> (Espiner & Hartnett, 2012)



It has been suggested that training on community inclusion has changed staff's views about the person and their futures.<sup>323</sup>

#### **5.3.4. Natural support**

Walker recommends that families should be trained in individualised supports, expectations for the planning process, self-advocacy, and funding strategies.<sup>324</sup> In an intervention designed to plan transition into older adulthood for families and their family member with intellectual disability, Heller and Caldwell provided training on financial and legal aspects and planning workshops to the intervention group.<sup>325</sup>

In summary, training has been identified as a core component of PCP implementation. Training recommendations have been put forward for the person who is the focus of the PCP, the families, PCP facilitators and staff implementing the plans.

#### **5.4. Establishing mechanisms for communication, monitoring and evaluation, review and development**

Robertson and Emerson recommend that plans are measurable, with a clear implementation strategy and assigned responsibility for implementing the strategy.<sup>326</sup> The effectiveness of PCP is directly related to the measurement of outcomes.<sup>327</sup>

Researchers have prioritised what happens after a PCP meeting takes place: follow up, evaluation and revision.<sup>328</sup> The primacy of what happens after the plan resonates with McCarron et al.'s findings, who found that key enabling factors of PCP were holding regular meetings and reviews.<sup>329</sup> Additional support to these findings comes from Parsons and colleagues who identified action as one of the key principles of PCP. The authors suggest that implementing the identified strategies and reviewing the person's situation over time increases the likelihood that planning will lead to optimal outcomes.<sup>330</sup>

In Wehmeyer, Garner, Yeager, Lawrence and Davis's study, project staff met with the participants at least twice a week to support implementation of PCP.<sup>331</sup> At these meetings, students presented self-monitoring data, discussed their progress and any barriers to progress. They had learned the skills to do this before the meeting. They had established mechanisms for ongoing communication, plan management and

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<sup>323</sup> (García Iriarte et al., 2016)

<sup>324</sup> (Walker, 2012)

<sup>325</sup> (Heller & Caldwell, 2006)

<sup>326</sup> (Robertson & Emmerson, 2007)

<sup>327</sup> (Robertson & Emmerson, 2007)

<sup>328</sup>(Hagner et al., 2012; Hagner et al., 2014; Wehmeyer et al., 2006)

<sup>329</sup> (McCarron et al., 2013)

<sup>330</sup> (Parsons et al., 2009)

<sup>331</sup> (Wehmeyer et al., 2006)



review. Students received training on how to self-direct their planning and make decisions that were specific to the transition process.

Recent research has provided evidence that a quality of life framework can be used to measure subjective as well as objective outcomes.<sup>332</sup> Verdugo, Navas, Gómez and Schalock argue that there is a close relationship between the core quality of life domains and 34 of the articles contained in the United Nations Convention on the Rights of Persons with Disabilities.<sup>333</sup> Furthermore, they suggest that the current status of these articles can be evaluated through the assessment of indicators associated with the eight core quality of life domains. The authors recommend that PCP is one strategy to operationalise and measure the articles in order to develop a metric that can be used to evaluate the progress and changes in people's status regarding their human rights and a life of quality. Verdugo and colleagues caution that interventions should be developed on the basis of empirically validated conceptual frameworks and by means of assessment instruments that are reliable and valid, to enable the development of provider profiles to guide continuous programme development and to enhance personal outcomes.

McCormack and Farrell conducted a study with the aim of assessing the current Quality of Life of adults with learning disabilities across a range of service providers in the Republic of Ireland, using Personal Outcome Measures.<sup>334</sup> They used stratified random sampling of adults with intellectual disabilities drawn from each of 22 Irish service providers. The study employed the Personal Outcome Measures instrument and followed standardised procedures for data collection and analysis. The survey instrument has 8 quality of life domains and 25 indicators. The scoring of each outcome is based on information from the person, another key informant who knows the person well, and if necessary, it is complemented with the review of existing documentation. Data collection takes about half a day for each person. The information is then reviewed and used to determine whether an outcome is present, what will help the person achieve or keep the outcome, and whether the outcome is a priority for the person. Quality of life, nonetheless, continues to be a contested construct.<sup>335</sup> Bigby and Knox used the “Senses Framework” to evaluate outcomes from the subjective perspectives of the person rather than from externally imposed criteria (such as quality of life instruments), aiming to make staff more attuned to aspects important to the person (sense of security, continuity, belonging, purpose, achievement, and significance).

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<sup>332</sup> (Claes et al., 2012; Verdugo et al., 2012)

<sup>333</sup> (United Nations, 2006)

<sup>334</sup> (McCormack & Farrell, 2009)

<sup>335</sup> (Bigby & Knox, 2009)



McConkey and colleagues provide a list of personalised support indicators that could be used as a bench-marking profile to assess the extent of personalisation achieved for each person (see Table 5.4).<sup>336</sup> The strongest indicator statistically is shown first.

**Table 5.4. Indicators of personalised support**

<b>Domain</b>	<b>Significant indicators</b>
Personalised accommodation	· Has a key to the house
Personalised supports	· Free to come and go
Relationships with people not paid	· Chooses own support staff
Valued roles in the community	· Had training in advocacy
Healthy lifestyle	· Has individual plan
Use of mainstream public Services	· Friends visited for a meal
Use of specialist disability Services	· Friends stayed over
	· Neighbours have provided help
	· Made new friends in past year
	· In paid employment
	· Has done voluntary work in the community
	· Helped neighbours
	· Less anxiety
	· Average weight
	· Participates in sports, swimming, fitness
	· Does not attend a day centre

Source: McConkey and colleagues<sup>337</sup>

In short, there is agreement that what happens after the plan (action, follow up, and outcomes measurement) is critical to accomplish outcomes and should become a priority of the planning process. Regular reviews of plans should be facilitated. The use of quality of life indicators has been proposed as an outcomes measurement method in the literature reviewed.

<sup>336</sup> (McConkey et al., 2013)

<sup>337</sup> (McConkey et al., 2013)





## 6. What evidence is available since 2005 on the effectiveness and implementation of PCP?

Despite the international research and policy endorsement of PCP and person centredness, most of the scientific literature focuses on its use and best practices but there is a lack of attention to its effectiveness.<sup>338</sup> Since 2005, only a handful of empirical studies have been conducted on the effectiveness of PCP. It is noticeable that the English study conducted by Robertson and colleagues in 2005 still provides the most robust account of empirical research on the effectiveness of PCP.<sup>339</sup> Dowling and colleagues state that one of the limiting factors to establishing PCP as an evidence based practice has been “the use of qualitative data, or simple reports and personal accounts” (p. 77).<sup>340</sup> Larger, longitudinal studies using randomised control samples should be used to demonstrate the effectiveness of PCP.<sup>341</sup>

This section aims to answer the question: How effective is PCP in accomplishing individual goals and how has it been implemented? The section focuses on the following areas:

- PCP outcomes
- Out of school transitions
- Transitions into older adulthood
- Social inclusion
- Independence
- Positive risk taking

### 6.1. PCP outcomes

Robertson and Emerson warned about the risk that plans would be developed “en masse” in the UK to comply with standards and national policy.<sup>342</sup> The authors advised that not only is it important that plans are developed but that plans are developed attending to quality, content, process, and life-style related outcomes. However, Robertson and Emerson pointed at a number of potential problems in relation to outcomes:

- Restricted range of goals
- Lack of long-term focus
- Inadequately prepared plans

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<sup>338</sup> (Claes et al., 2010; Dowling et al., 2007; Parsons et al., 2009; Robertson & Emerson, 2007; Robertson et al., 2006; Taylor & Taylor, 2013)

<sup>339</sup> (Robertson et al., 2005, 2006; Robertson et al., 2007; Robertson et al., 2007; Wigham et al., 2008)

<sup>340</sup> (Dowling et al., 2007)

<sup>341</sup> (Robertson et al., 2007)

<sup>342</sup> (Robertson & Emerson, 2007)



- Lack of information on how and by whom goals are to be implemented
- Vaguely expressed goals
- Preferred activities not corresponding to the actual preferences of service users
- Goals remain unmet.

Despite the challenges identified by Robertson and Emerson, the literature reviewed reports on the effectiveness of PCP achieving two types of outcomes:

- Indirect outcomes resulting from participation in PCP
- Outcomes targeted in PCP.

### **6.1.1. Indirect outcomes resulting from participation in PCP**

A number of studies have reported on indirect individual gains resulting from participation in PCP. For example, follow up qualitative research on the study carried out by Robertson and colleagues in 2005 identified that the most common reported benefit from participation in PCP was the increased number of activities and opportunities followed by a fresh look at the person and their life, participants feeling better, confident, and happy.<sup>343</sup> For nearly half of the participants, a main benefit of PCP was that they felt better in themselves in terms of happiness or self-esteem. Additional benefits were reported in the areas of empowerment, control and choice.

Claes, Van Hove, Vandeveld, Van Loon and Schalock highlighted the following participation outcomes in their review: involvement of the person or his or her family, improved communication, teamwork, development of a larger vision, incorporation of the individual's desires in written goals, and a significant effect on parental participation.<sup>344</sup>

Self-determination and autonomy have been reported as benefits of PCP in a number of studies.<sup>345</sup> Participants in Espiner and Hartnett's study reported that comments from the participants with an intellectual disability demonstrated that most of them felt they had gained great ownership, a sense of control in their lives and autonomy with the introduction of the new person centred facilitated approach.<sup>346</sup> In a study conducted in Illinois, following training and facilitation of planning, target group participants demonstrated increased self-awareness and self-knowledge of their preferences, had a stronger sense of accomplishment and had greater clarity on the support needed to accomplish goals.<sup>347</sup>

In short, participation in the planning process results in benefits to the person (happiness, autonomy, self-determination), the planning team (involvement, team

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<sup>343</sup> (Wigham et al., 2008)

<sup>344</sup> (Claes et al., 2010)

<sup>345</sup> (Espiner & Hartnett, 2012; García Iriarte, 2009; Hagner et al., 2012; Wehmeyer et al., 2009)

<sup>346</sup> (Espiner & Hartnett, 2012)

<sup>347</sup> (García Iriarte, 2009)



work), although these may have not been targeted as goals in people's plans. The next section focuses on individual goals targeted in the plans.

### **6.1.2. Outcomes targeted in PCP**

The most common goals identified by participants in the studies reviewed were in the areas of community inclusion, social networks, work, leisure, education and learning. A note of caution should be made here as there is no control over the independence in choice making that participants in these studies had when setting their individual goals. For example, Taylor and Taylor noted in their review that an earlier study had identified little evidence of goals set in the areas of intimate relationships and marriage in PCP for people with intellectual disabilities.<sup>348</sup>

Relationships are a key area of interest of people with intellectual disability but significant challenges exist within services to promote relationships.<sup>349</sup> Furthermore, a common limitation to the studies analysed in this report is that the longitudinal timeframe used, generally about two years, may not be enough to document changes in the goals set by people with intellectual disabilities.<sup>350</sup> Other methodological limitations to conclude on the effectiveness of PCP to accomplish outcomes are the detail of description of the different components of the PCP process, along with a lack of control that the PCP intervention was implemented adequately.<sup>351</sup> In the next section, we look in more detail at the following outcomes targeted in PCP: out of school transition, transition into older adulthood, social inclusion, independence and risk taking.

## **6.2. Out of school transition**

A combination of personal characteristics and best practice school programmes has been found to significantly predict out of school outcomes.<sup>352</sup> The National Longitudinal Transition Study 2 followed youth with disabilities as they graduated from high school and began adult life in the USA.<sup>353</sup> A study conducted by Pappay and Bambara involved a nationally representative sample of youth with disabilities aged 13 to 16 on December 1, 2000 who were followed over a period of 10 years. The study found that personal factors such as high school completion, family income, parent expectations for employment, parent expectations for postsecondary education, and urbanicity were found to be significant predictors of at least one the following outcomes up to 2 and 4 years out of high school:

- Employment
- Post-secondary education

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<sup>348</sup> (Taylor & Taylor, 2013)

<sup>349</sup> (García Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014)

<sup>350</sup> (McCarron et al., 2013; McConkey et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006)

<sup>351</sup> (Claes et al., 2010)

<sup>352</sup> (Papay & Bambara, 2014)

<sup>353</sup> (Papay & Bambara, 2014)



- Enjoyment of life
- Social interactions.

A combination of personal characteristics and best practice school programmes significantly predicted the outcome. Next, we look at best practice school programmes.

Wehmeyer et al. evaluated a multistage transition support model called Beyond High School that involved preparation, a planning meeting and implementation with participants with intellectual disability (n=13) and learning disability (n=2) aged between 18 and 21.<sup>354</sup> The evaluation of the model identified that most students (94%) achieved their goals to a level considered satisfactory by their teacher.<sup>355</sup> A third of the participants were exceeding the teacher's expectations. The model consists of 3 stages:

- In stage 1 (preparation) students are supported to establish goals, develop an action plan, learn how to self-evaluate and how to self-monitor their goals. Students receive training on how to self-direct their planning and make decisions specific to the transition process. Students develop skills in goal setting and action planning using the *Self-Determined Learning Model of Instruction* teaching model.<sup>356</sup> Using this model, students learn what questions to ask themselves in order to identify their goals and plan how to achieve them
- In stage 2 (PCP meeting), students present their goals. Those present provide guidance and suggestions, but do not criticise or replace the goals. They support and enable the student to provide informed consent to implement the plan
- Stage 3 (implementation) involves the implementation of PCP with supports identified in the previous stage, monitoring of progress achieving the goals, evaluation of success making revisions to the plan or the goals accordingly.

The authors propose that activities such as those in the Beyond High School Model (including PCP) are a means to increase self-determination and to achieve active involvement for students in their transition from school.

A second study on the effectiveness of transition interventions conducted by Hagner et al. used a randomised control trial design to measure the impact of a transition planning intervention on 47 young people with autism spectrum disorder aged between 16 and 19.<sup>357</sup> In a similar manner to the study described above by Wehmeyer et al., the intervention consisted of three elements:

- Group training on the transition process and on PCP

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<sup>354</sup> (Wehmeyer et al., 2006)

<sup>355</sup> (Wehmeyer et al., 2006)

<sup>356</sup> (Wehmeyer, Palmer, & Agran, 2000)

<sup>357</sup> (Hagner et al., 2012)



- PCP meetings
- Follow-up assistance for plan implementation, for example, job shadowing.

In Hagner et al.'s study, however, training was provided to families. The PCP component consisted of two planning facilitators assisting each student and family through a structured planning process to develop a transition plan. Hagner et al. reported that those involved in PCP had significantly higher expectations for the future, higher self-determination and higher vocational decision making ability than the control group.<sup>358</sup>

Although with a very small sample, Mazzotti, Kelley and Coco's results provide further support of transition interventions to increase participation of people with intellectual disabilities. They found that the use of the Self-Directed Summary of Performance tool was associated with increased participation during PCP meetings for 3 participants with intellectual disabilities and this generalised to work interviews.<sup>359</sup> Generalisation to other situations or settings was measured in two ways: comparing participation in a PCP meeting before the intervention and afterwards and observing participants in an interview with an employer.

The three-stage interventions (preparation, meeting and implementation) appear to be effective to accomplish self-selected goals and also personal skills such as autonomy and self-determination. This finding is further supported by Kaehne and Beyer, who highlight the limitations of transition interventions focused only on the planning meeting. The authors concluded that organising transition review meetings in a PCP manner by itself does not produce improved post-school options and hence better choices.<sup>360</sup> They carried out a documentary analysis of 44 person centred transition review meetings.<sup>361</sup> The planning system included a transition review meeting, the production of accessible plans and setting clear goals. The school appointed a transition coordinator to organise review meetings and to deliver them in a person-centred way. The coordinator was trained in PCP and used PCP transition templates which guided the information to be included in the plan. What the meetings can do, according to the authors, is to provide an opportunity for people to express their needs and preferences. The authors echo the concerns of Claes et al.'s systematic review and question whether PCP is just a more person-centred way to enter a service, rather than making any real difference.<sup>362</sup>

Hagner, May, Kurtz and Cloutier explored what strategies and supports were used to help transition-aged youth with autism spectrum disorder to participate in PCP transition meetings.<sup>363</sup> Flip chart notes from the meetings and facilitator progress

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<sup>358</sup> (Hagner et al., 2012)

<sup>359</sup> (Mazzotti et al., 2015)

<sup>360</sup> (A Kaehne & Beyer, 2014)

<sup>361</sup> (A Kaehne & Beyer, 2014)

<sup>362</sup> (Claes et al., 2010)

<sup>363</sup> (Hagner et al., 2014)



notes were analysed qualitatively. The 47 participants in this study were aged 16 years and older. Strategies facilitating participation of youth in planning included:

- Individualised preparation for meetings
- Informal activities to build rapport between the planning facilitator and the youth
- Flexible meeting designs
- Distance attendance
- Support for alternative means of communication.

Morningstar et al. suggest five indicators of quality transition programmes from secondary school onwards:<sup>364</sup>

- Interagency collaboration
- Student-centred transition
- Curriculum and instruction focused on specific post-school outcomes
- Family involvement
- Student self-determination.

While the authors do not refer to PCP directly, the evidence indicates that using PCP can support success in these areas by providing a forum for students and parents to take a central role. However, PCP alone is not sufficient and needs to happen in the context of good interagency collaboration, support for students and specific training as needed.<sup>365</sup>

Two descriptive research papers have also pointed at the need to develop inter-agency collaboration for more effective transitions out of school.<sup>366</sup> Kaehne, however, cautions against the effectiveness of protocols to detail inter-agency work. Kaehne examined the transition protocols in place for intellectual disability partnerships in 22 local authorities in Wales in order to see how PCP was reflected.<sup>367</sup> Protocols are supposed to detail how service providers and service users work together in a mutually agreed fashion. In this way, they support partnerships and are seen as critical for interagency work. Kaehne acknowledges that while a protocol is only one part of the picture, it may be a tool to support effective PCP. However, protocols were implemented through a variety of approaches and with different quality, further suggesting a lack of their effective use. Protocols, furthermore, did not provide indicators of involvement of the youth transitioning in other relevant agencies such as self-advocacy or employment organisations.<sup>368</sup>

A study conducted in Ireland with a small sample of parents of children with mild intellectual disability found that the transition process was stressful, uncertain and

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<sup>364</sup> (Morningstar et al., 2010)

<sup>365</sup> (Morningstar et al., 2010)

<sup>366</sup> (Kleinert, Jones, Sheppard-Jones, Harp, & Harrison, 2012; Yamamoto et al., 2014)

<sup>367</sup> (Kaehne, 2010)

<sup>368</sup> (Kaehne, 2010)



problematic.<sup>369</sup> Seeing their young person increase in confidence and enjoy their post-school setting, however, was reported as a positive aspect of the transition. Parents identified a number of service level barriers to successful transition:

- Lack of parental involvement in decisions and planning
- Lack of information about options
- Lack of options
- Waiting lists
- Lack of person-centred practices in vocational training
- Lack of coordination between child and adult services
- Problematic interactions with staff in adult services and
- Feeling that the parents' voice was not heard by staff.

The authors assert that early planning that is parent and family centred is key to future developments.

In summary, the studies included in this literature review indicate that multi-stage transition programmes including individualised preparation and training, facilitation of planning meetings, and follow up lead to successful outcomes, although it should be noted that planning in itself is not enough to accomplish goals. This is consistent with the findings from a longitudinal transition study that indicates that a combination of personal characteristics as well as school practices predicts post-school outcomes. Successful preparation for planning involves training on identifying preferences and goals, building self-advocacy skills, and choosing who is present at the meeting. The planning meeting should be flexible and supportive of the person to present the goals previously identified, involving support from other stakeholders to refine the goals, to identify the necessary support to implement the plan and to agree on the best strategies to accomplish the plan. Strategies to facilitate participation of youth in planning include individualised preparation for meetings, flexible designs, informal activities to develop the relationship with the facilitator and the provision of alternative means of communication. Family involvement and inter-agency collaboration have been identified as key challenges to the out of school transition process. However, data from one study questions the effectiveness of protocols to set the standards for partnership work.

### **6.3. Transition into older adulthood**

Another time of transition that is important to consider is as people, both people with disabilities and their carers/family members,<sup>370</sup> get older. The research reviewed suggests that both groups need to be involved in planning for the future. Taggart and Trainor found that carers in Northern Ireland had clear preferences for a future plan but they were upset thinking about the future. Craig and Cartwright found that

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<sup>369</sup> (Gillan & Coughlan, 2010)

<sup>370</sup> The terms carers, caregivers and family members are used in the literature reviewed. In this report, the term carer is used to refer to carers who are family and non-family members.



carers are not used to thinking about themselves and that the challenging behaviours of those they care for prevented them from spending time ‘on their own’.<sup>371</sup> The authors call for service providers to support carers to proactively plan for the future.<sup>372</sup> Bowey and McGlaughlin also found that carers of people with intellectual disabilities were very aware of the need for alternative housing or support in the future and had clear preferences about their future options. Despite this, many were unwilling or did not feel ready to make plans for the future. The authors recommend a pro-active approach where planning is supported long before a crisis situation. The authors also recommend involving adults with intellectual disabilities in planning for their future.<sup>373</sup> Another study found that people with intellectual disabilities want the same things as everybody else but they felt lonely and some wanted to move into their own homes.<sup>374</sup>

Besides the concerns of people with intellectual disabilities and their carers, Bibby identified, through a review of the literature, the following barriers for adults with intellectual disabilities living with older carers in the UK to engage in future planning:<sup>375</sup>

- Lack of confidence in present and future provision
- Difficult relationship with professionals
- Mutual care/interdependency (between family members)
- Lack of information
- Painful/difficult subject
- Carer purpose and identity (the caring role provides a structure and purpose to the lives of carers)
- Carer sense of duty (moral argument to continue to provide care)
- Service-user fear of unknown (living away from the family)
- Carers’ concern regarding loss of control (over their family member’s quality of life)
- Service-user unwilling to leave home.

Heller and Caldwell also found challenges to planning including; trusting professionals, emotional struggles with the system and facing a difficult subject.<sup>376</sup> In a study by Craig and Cartwright, staff mentioned that families do not access services until they can no longer continue the care of their family member.<sup>377</sup>

The literature review for effective interventions into third age identified a successful transition intervention into older adulthood, reported by Heller and Caldwell. The

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<sup>371</sup> (Craig & Cartwright, 2015)

<sup>372</sup> (Taggart & Trainor, 2012)

<sup>373</sup> (Bowey & McGlaughlin, 2007)

<sup>374</sup> (Craig & Cartwright, 2015)

<sup>375</sup> (Bibby, 2013)

<sup>376</sup> (Heller & Caldwell, 2006)

<sup>377</sup> (Craig & Cartwright, 2015)





authors conducted an intervention developed to support aging caregivers and adults with developmental disabilities to plan for the future.<sup>378</sup> The families involved took concrete steps in future planning and this led to a decrease in caregivers' burden and to an increase in the opportunities for daily choice making.

The intervention is called *The Future is Now: A Future Planning Training Curriculum for Families and their Adult Relatives with Developmental Disabilities*. It is a peer support model which includes the person in the planning process. The intervention consisted of a legal and financial training session which was attended by both the intervention and control groups (29 families). This was followed by five small group workshops for the intervention group (10 families) co-facilitated by families and individuals with developmental disabilities. The workshops covered:

- Introduction to future planning
- Relationships, supports and community involvement. This involved outlining circles of support
- Residential and housing issues and options
- Preferences and options for work, retirement and leisure
- Identification of a future caregiver and a future planning goal.

Towers and Wilkinson present an account of using PCP for people with intellectual disability and dementia. The authors of the model suggest that the model, independent from services and organisations, can be used by practitioners across intellectual disability, dementia and family support organisations.<sup>379</sup> However, this model has not been validated empirically. Key elements of the model are:

- Flexibility for both families and professionals to lead on the process. Families' knowledge of the person and professionals' knowledge of dementia can be combined to provide continuity for the care of the person
- The focus of the plan is the person. Among the tools recommended by Towers and Wilkinson to plan with the person are: history/story of their life, work out what is important to the person (help maintain wellbeing and reduce stress, for example, preferences), and important for the person (keep the person safe, well and healthy, for example, medication), what constitutes a good day, and a bad day for them, make a "people in my life" map, develop a profile of the ideal person by whom they would like to be supported
- Develop emergency plans to ensure continuity of support if there is an emergency. This may involve the family in thinking about possible emergencies, the supports that need to be provided and, importantly, avoiding to move the person to another place for which the "people in my life" map can be used
- Provide a network of support that can help decision making.<sup>380</sup>

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<sup>378</sup> (Heller & Caldwell, 2006)

<sup>379</sup> (Towers & Wilkinson, 2014)

<sup>380</sup> (Towers & Wilkinson, 2014)



In short, although the research indicates that both people with intellectual disabilities and their carers should be involved in planning for the future, there are several challenges for effective involvement in planning. One intervention reporting positive results focused on legal and financial training followed by planning workshops for families. Only one model focusing on people with intellectual disability and dementia has been found through this literature review. The model describes how planning should be flexible, be focused on the person, include emergency planning and informal support. However, the model lacks empirical validation.

#### **6.4. Social inclusion**

Howarth, Morris, Newlin and Webber define social inclusion as encompassing access to social roles: “Social inclusion means ensuring that people with learning disabilities have full and fair access to activities, social roles and relationships directly alongside nondisabled citizens” (p. 4).<sup>381</sup> Cobigo, Oullette-Kuntz, Lysaght and Martin define social inclusion as “a series of complex interactions between environmental factors and personal characteristics that provides opportunities to:

- Access public goods and services
- Experience valued and expected social roles of one’s choosing based on his/her age, gender and culture
- Be recognised as a competent individual and trusted to perform social roles in the community
- Belonging to a social network within which one receives and contributes support” (p. 82)<sup>382</sup>

Based on their literature review findings, Cobigo and colleagues make the following suggestions on social inclusion:<sup>383</sup>

- The focus of social inclusion should be to develop a sense of belonging and a social network that provides natural and informal supports
- Social inclusion should be based on the needs, expectations and choices of the person and not on the dominant societal values and lifestyles by which people can be judged if they do not achieve them
- The value of an individual’s contribution to the community should be determined by the goals identified by the person and not by what is typical in the group. This is achieved through reciprocity and trust among members of the group
- Social inclusion should be evaluated through subjective measures of one’s social belonging and well-being and move beyond the number and frequency of activities undertaken in the community. Otherwise, social inclusion efforts risk becoming “social exposure” instead of “real participation”

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<sup>381</sup> (Howarth, Morris, Newlin, & Webber, 2014)

<sup>382</sup> (Cobigo et al., 2012)

<sup>383</sup> (Cobigo et al., 2012)



- Persons should be satisfied with their role performance and their contributions recognised by others
- People tend to seek interactions with others who share common interests. As a consequence, social inclusion should be understood as relative to an individual within the group to which he or she wants to belong. For example a group formed by people with intellectual disabilities is a form of community inclusion if that is the group that a person with intellectual disability wants to belong to.

Within this conceptualisation of social inclusion, organisations should review their mission as connecting people and their communities and establishing relationships with other organisations.<sup>384</sup> The role of direct support professionals also needs to be re-defined from one of “skills developer” to one of “community connector”.<sup>385</sup> In this sense, PCP is a primary framework for ensuring that people are included in their communities and in social networks in a manner consistent with their preferences.<sup>386</sup>

A growing body of evidence demonstrates the effectiveness of community-based supports and services that are person-centred and help people assume meaningful roles and relationships in society.<sup>387</sup> This section reviews the evidence on the effectiveness of PCP to increase social inclusion. It also focuses on the effectiveness of two strategies, which are also part of PCP: goal setting and circles of support.

#### **6.4.1. PCP**

In a literature review conducted to examine the evidence base regarding interventions to increase social participation, PCP was found to be among the most effective interventions.<sup>388</sup> Another literature review examining the effectiveness of PCP found that significant change was most apparent in relation to improved social networks and community involvement.<sup>389</sup> Both literature reviews strongly drew from Robertson et al.’s study.

Robertson et al. conducted a two-year longitudinal study of 93 people with intellectual disabilities living in four localities in England.<sup>390</sup> These were the first people with intellectual disability in their respective organisations to be part of a PCP development. The study used an intervention to train staff and managers on PCP over a period of two years. The training was delivered to 16 facilitators at each site over 20 sessions, each session was 5 to 8 hours long. The goal was for people to be supported to be contributing members of their communities and to lead fulfilling

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<sup>384</sup> (Gomez, 2013)

<sup>385</sup> (Gomez, 2013)

<sup>386</sup> (Gomez, 2013)

<sup>387</sup> (Cobigo et al., 2012)

<sup>388</sup> (Howarth et al., 2014)

<sup>389</sup> (Claes et al., 2010)

<sup>390</sup> (Robertson et al., 2005, 2006; Robertson et al., 2007; Robertson et al., 2007)



lives. The development process focussed on building people's capacity to make plans. The following strategies were employed:

- Training of facilitators on PCP
- Supporting facilitators through individual sessions with the coordinator of PCP at each organisation
- Investing in families, self-advocates and other community members on leading the planning
- Considering the support needs to implement the plans
- Considering how organisations need to change.

Modest positive changes were identified in areas including social networks, contact with friends and family, community based activities, scheduled daily activities and choice.<sup>391</sup> In another article relating to the same longitudinal study, Robertson and colleagues note that although their previous study suggested PCP was efficacious overall, it worked better for some individuals than others.<sup>392</sup> Their results suggest that, in terms of participants' characteristics, people with autism, mental health, behavioural or emotional problems were less likely to receive a completed plan. Moreover, if they did, they were less likely to experience positive change.

Howarth and colleagues concluded in their literature review that PCP is helpful, but not sufficient, to promote social participation (social contacts and involvement in social activities).<sup>393</sup> They recommended, based on their findings, employing approaches that focus on naturally occurring opportunities for social interaction to increase the social networks of people with intellectual disabilities.

Two additional strategies have been reported to have an impact on social inclusion: goal setting and circles of support.

#### **6.4.2. Goal setting**

Goal setting has also been reported as a strategy to increase social inclusion of people with intellectual disabilities. Although goal setting is an integral part of PCP, it can also be used as a stand-alone strategy to achieve social inclusion. The two studies described next used goal setting not as part of a long term plan for the person to achieve a number of outcomes but as a short-term strategy to achieve social inclusion goals.

In the Northern Irish context, McConkey and Collins explored personal goal setting to promote the social inclusion of people with intellectual disability.<sup>394</sup> McConkey and Collins' study involved 130 adult participants who lived in a variety of types of supported housing (both congregated settings and supported living projects) in

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<sup>391</sup> (Robertson et al., 2006)

<sup>392</sup> (Robertson et al., 2007)

<sup>393</sup> (Robertson et al., 2006)

<sup>394</sup> (McConkey & Collins, 2010)



Northern Ireland.<sup>395</sup> The study used a goal setting approach in three stages including an interview and two review meetings. Key workers were invited to be present at the first interview. After background data was collected, participants were invited to set three goals related to doing things with people and being involved in the community. Goals were set around social activities (e.g., going out for a meal or on holidays), entertainment (e.g., going to the cinema), sport (e.g., play football), independence (e.g., using buses), work and training (e.g., placements, attend classes), and social contacts (e.g., meeting and visiting friends). McConkey and Collins classified the goals of participants into categories which included (from most to least popular): social activities, entertainment activities, sporting activities, activities to increase independence, work or training activities, activities to increase social contacts, and activities to increase contact with family.<sup>396</sup> These were subsequently listed on a 'Goal Record Sheet'.

Review meetings and interviews were held after 9 and 18 months to see if goals had been attained and also to identify what had helped or hindered individuals in goal accomplishment. At these meetings additional goals were set or existing goals were amended. The most important factor helping participants achieve their goals was staff assistance. Other factors involved accessibility, availability of volunteers and sourcing work placements, support and contact with family and friends and their own independent skills. Factors that prevented people from achieving goals were planning, behaviour problems, ill health and personal competence, money and the lack of social contacts. The authors suggest that their findings imply that: "Certain gains can accrue from using goal setting to enable many, but not all tenants, in various accommodation options to participate in more social activities" (p. 142). Moreover, the findings highlight the pivotal role support staff, as well as individuals, play in facilitating social and community inclusion.

Mirza and Hammel pilot-tested in a controlled trial a consumer-directed approach to service delivery, the Assistive Technology Long-Term Advocacy and Support (ATLAS), with 77 people with intellectual disabilities living in the community in the USA.<sup>397</sup> The intervention consisted of five sessions held over 3 months focused on people with intellectual disabilities' home, current living situation or the neighbourhood where they lived. They worked with an occupational therapist to identify issues, set goals related to community living and participation, and to problem solve how to address these issues through environmental strategies (physical modifications, technology, social environment changes, etc.). In the last session, a disability advocate worked with the team to provide disability related information, resources and networks in the community. Participants identified two sets of goals. Basic self-care goals aimed at increasing or maintaining independence/safety in mobility or activities of daily living. The other category included those goals directed towards promoting community participation, social

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<sup>395</sup> (McConkey & Collins, 2010)

<sup>396</sup> (McConkey & Collins, 2010)

<sup>397</sup> (Mirza & Hammel, 2009)



interaction, meaningful engagement in recreational activities, and promoting advocacy. Systems level advocacy and action followed by the use of assistive devices were employed to address participation/environmental/systems level goals. Participants' satisfaction with goals showed a significant positive correlation with their perceived performance (goal achievement), and this was higher for the intervention group compared to the control group. These findings indicate the positive contribution of the intervention towards the removal of environmental barriers and opportunities for people with disabilities to identify and direct goal attainment.

In summary, goal setting and goal attainment are inherent components of PCP. However, they can also be used independently of PCP to improve community participation. Findings from McConkey and Collins indicate that goal setting can support some people with intellectual disabilities to participate in more social activities. Mirza and Hammel concluded that a consumer directed service delivery approach using goal attainment can enable people with intellectual disabilities to remove environmental barriers to improve community inclusion. In the next section, we review circles of support.

#### **6.4.3. Circles of support**

Networks and circles of support, which could be considered equivalent to PCP, are also increasingly used to help people with intellectual disabilities live a good life.<sup>398</sup> Wistow, Perkins, Knapp, Bauer and Bonin note, however, that despite their compatibility with current policy demands, few circles currently exist and there is little evidence of their effectiveness.<sup>399</sup>

Wistow and colleagues explored the use of 5 pre-existing circles of support in North West England organised around adults with moderate to profound learning disabilities to enable people with learning difficulties to live full lives in their communities.<sup>400</sup> The five circles studied were heterogeneous in terms of type and level of disability. Each circle included the individual and a selection of friends, family, close acquaintances of the family and support staff.

Despite the small sample and the lack of a comparison group, they found that participants universally attributed their current quality of life to their respective circle. Findings specifically related to community inclusion indicate that:

- Circles were seen by all participants as the key factor in enabling individuals live well in their community
- Circles were a form of community building
- Circles members had developed and utilised a range of community resources to promote social inclusion.

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<sup>398</sup> (Wistow et al., 2016)

<sup>399</sup> (Wistow et al., 2016)

<sup>400</sup> (Wistow et al., 2016)



In summary, the literature reviewed provides a nuanced conceptualisation of social inclusion involving access to the community, experience of social roles and recognition of one's competence, and development of social networks. The findings of this review indicate that PCP and personal goal setting and attainment strategies can help achieve community inclusion. Although the evidence is weaker, circles of support are also attributed an important role in maximising inclusion of people with intellectual disabilities in their communities.

## 6.5. Independence

Kendall and Cameron identified that most participants with an intellectual disability claimed independence is about “having the right level of support so that you do what you can but you are not left in a position where you struggle” (p. 267).<sup>401</sup> The literature reviewed provides findings about independence conceptualised as doing things without support and having control over people's lives.

Independence has been reported as one of the main benefits resulting from participation in PCP.<sup>402</sup> In the literature review by Claes et al., however, less change was identified in choice making compared to social inclusion.<sup>403</sup> Robertson and colleagues found that people with an intellectual disability had a 2.8 times greater chance of having more choice in their lives following PCP development.<sup>404</sup> However, these findings varied according to personal characteristics. People with mental health problems and emotional or behavioural problems were less likely to benefit if they did receive a plan in the area of choice while women were more likely to benefit in the area of choice. Having a care manager increased the likelihood of having choice, as did living in a less affluent area.<sup>405</sup>

Despite a reported smaller influence on independence than on social inclusion, PCP enables people with intellectual disabilities to set goals to achieve independence.<sup>406</sup> For example, McCarron and colleagues found that participation in PCP resulted in an increase in goal setting in the area of independence and autonomy.<sup>407</sup> McCarron et al. conducted an action research study over two years with the aim of establishing a PCP approach to care and support.<sup>408</sup> The study used a seven-phase action research design which included a collaborative approach for data collection through the use of inquiry groups and network groups. Training on PCP was delivered to staff in 5 pilot sites. Over the duration of the project, 114 meetings were facilitated on the

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<sup>401</sup> (Kendall & Cameron, 2014)

<sup>402</sup> (Wigham et al., 2008)

<sup>403</sup> (Claes et al., 2010)

<sup>404</sup> (Robertson et al., 2006)

<sup>405</sup> (Robertson et al., 2007)

<sup>406</sup> (McCarron et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006; Sheerin et al., 2015; Wigham et al., 2008)

<sup>407</sup> (McCarron et al., 2013)

<sup>408</sup> (McCarron et al., 2013)



development of PCP for 22 service users. Examples of goals included developing skills in activities of daily living such as cooking and traveling independently and having control over their lives, such as getting one's own place to live. Key enabling factors of PCP included:

- Staff and organisational support for PCP
- Staff training on PCP
- Family and multi-disciplinary involvement
- Regular meetings
- Establishing meaningful goals
- Regular reviews
- Service culture promoting PCP.

Participants' abilities were enhanced when they were given greater opportunities by staff to be independent. Some service users benefited from the involvement of informal support such as family and friends to ensure the implementation of community oriented independence focused goals. While there was a reported increase of 'independence' goals established for most individuals, some of which involved community participation, during the duration of the research project the Comparison of Quality of Life Questionnaire mean scores at baseline and post-research project showed no statistically significant difference in empowerment and independence.

Living more independently and having a job is related to enhanced personal outcomes.<sup>409</sup> McConkey and Collins also found that having the ability to complete activities independently led to goal accomplishment.<sup>410</sup> Lawlor, Spitz, York and Harvey found a positive relationship between targeting intentional skill teaching in PCP with increased ability of individuals to live more independently in communities and rely less on paid support.<sup>411</sup> Goals in the areas of material well-being (personal finances, employment, and management of home) were correlated with living more independently. The strongest correlation found was between goals containing skill development and goals involving communication.<sup>412</sup> The role of support staff to provide individualised support and implement plans to achieve independence is also well documented.<sup>413</sup> Informal supports, such as family and friends, have also been identified as enabling independence-focused goals accomplishment.<sup>414</sup>

### **6.5.1. Accessibility of plans**

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<sup>409</sup> (Claes et al., 2012)

<sup>410</sup> (McConkey & Collins, 2010)

<sup>411</sup> (Lawlor et al., 2013)

<sup>412</sup> (Lawlor et al., 2013)

<sup>413</sup> (Fitzsimons, 2012; García Iriarte, 2009; McCarron et al., 2013; McConkey & Collins, 2010; Robertson et al., 2006; Sheerin et al., 2015)

<sup>414</sup> (McCarron et al., 2013)





Increased independence of people with intellectual disabilities is enabled by accessible information and availability of support. Espiner and Hartnett reported that participants with an intellectual disability found that the accessibility of the plans increased their independence in reading and evaluating the plan while others required staff facilitation.<sup>415</sup> This independence enhanced their abilities to carry out their role in the process much more effectively.

### **6.5.2. Funding**

Person centred-funding is one way to enable flexibility for self-determination and community participation of people with disabilities.<sup>416</sup> According to Parsons and colleagues, individualised funding offers new opportunities for person centred-approaches.<sup>417</sup> Indeed, a literature review conducted by Dowling and colleagues concluded that inflexible funding has been identified as another challenge to the implementation of PCP.<sup>418</sup>

Fisher and colleagues conducted a study to examine the effectiveness of individual funding of disability support in Australia.<sup>419</sup> Individual funding is defined in the study as “a portable package of funds allocated for a particular person that facilitates control over how they purchase their disability support needs” (p. 4). One of the study findings is that individual funding facilitates control and choice in support provision. People’s choices are enhanced by the following strategies: individual needs assessments, planning and goal setting processes, and flexibility to spend the funds. Packages that can be managed by the person, their family or a facilitator are more likely to be responsive to people’s preferences than those that must be spent through a single service provider. Information on individual funding is given through planning and reviews and it should support choice and decision making in support planning. The study also found comparable outcomes for people using individualised funding to those of the general population in terms of personal wellbeing, physical and mental health. People were happy with their social relationships and community participation.

However, independence of persons with intellectual disabilities is conditioned by opportunities available in the communities where they live and by the choices offered by staff. Robertson and colleagues identified barriers to the accomplishment of goals that related to the availability of services, more specifically, a limited choice of day services, a limited choice of housing, waiting lists for services, and limited employment opportunities.<sup>420</sup>

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<sup>415</sup> (Espiner & Hartnett, 2012)

<sup>416</sup> (Kirkman, 2010)

<sup>417</sup> (Parsons et al., 2009)

<sup>418</sup> (Dowling et al., 2007)

<sup>419</sup> (Fisher et al., 2010)

<sup>420</sup> (Robertson et al., 2007)



In short, independence has been reported as one of the main benefits resulting from participation in PCP, although this is conditioned by personal characteristics and available opportunities. People benefit from accessibility modifications and support, formal and informal, to achieve independence. Living independently and having a job are also associated with better outcomes. PCP enables people to set goals in the area of independence, such as performing activities without support and having control over their lives. Individualised funding has been found to facilitate control on the purchase of disability support. However, there is scant evidence that attributes PCP as the cause of increased independence.

## 6.6. Positive risk taking

As individuals lead more independent lives, the risk associated with the activities in which they are involved is likely to increase. Positive risk management is seen as a way of decreasing inhibiting care practices and reducing societal inequalities, while addressing safety concerns.<sup>421</sup> Hillman et al. identified that ‘a good life’ for a person with an intellectual disability required the person to be happy and safe within their own home.<sup>422</sup> However, the literature reviewed identifies two major limitations to positive risk taking: organisational policies on risk taking and staff concerns about risk.

Robertson et al. found participants were 50% more likely to be perceived by staff to be at risk in or out of the home or from traffic following the introduction of PCP.<sup>423</sup> These changes may be explained as participants were now leading a much fuller life which was likely to have involved an increase in some predictable risks (for example, from traffic). In another example, McCarron and colleagues found that the use of centralised service accounts was perceived as a barrier to implementing PCP in terms of autonomy and choice. However, staff participants recognised that the burdensome procedure to manage service users’ money also aimed at protecting their finances and staff.

Management of positive risk taking involves a reformulation of organisational policies that empower people to develop skills to manage their risks and take responsibility for them and a review of staff attitudes towards independence and risk.<sup>424</sup> In Hillman’s study, participants viewed barriers to achieving such a person centred approach included public service system regulations which restricted the individuals opportunities because of concerns regarding liability, and health and safety issues. Service structures were inflexible and struggled to adapt and cater for individual needs.<sup>425</sup> Others have found that staff concerns about risk limited the opportunities offered to people in their care.<sup>426</sup> McConkey and Collins found that often goals set

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<sup>421</sup> (Hillman et al., 2012)

<sup>422</sup> (Hillman et al., 2012)

<sup>423</sup> (Robertson et al., 2006)

<sup>424</sup> (Hillman et al., 2012)

<sup>425</sup> (Hillman et al., 2012)

<sup>426</sup> (Hollomotz, 2014; McCarron et al., 2013)



by people with an intellectual disability as part of their PCP were not carried out because staff had not completed risk assessments. This was less likely to occur where there was 24 hour staff support and this was provided on an individualised basis.<sup>427</sup> However, the finding by McConkey and Collins needs to be interpreted with caution because availability of 24 hour staff means that there is more staff time in a day to complete formal procedures such as risk assessment. Policies on risk assessment have been reported to be over-protective and often limit accomplishment of individual outcomes.<sup>428</sup>

Hollomotz conducted a study on the experiences of people with intellectual disabilities making everyday choices.<sup>429</sup> She found that often the choices offered by staff were tokenistic and restricted. The researcher also suggests that people's lack of opportunities to participate in activities can lead to deskilling and disempowerment, which may increase their vulnerability. Many participants in Hollomotz's study were used to over protection by carers, which they enforced, and in turn, to having limited opportunities for choice making.<sup>430</sup> Hollomotz states, "the assumption of 'vulnerability' can thus become a self-fulfilling prophecy" (p. 240).<sup>431</sup>

Hollomotz accepts that providing support for the person with an intellectual disability to make decisions is often a struggle between providing safe care and assisting people in developing independence.<sup>432</sup> This finding resonates with Windley and Chapman's study, which also found that support staff recognise the vulnerability of this population and the conflict staff experience between providing service users with choice and managing scarce resources and risk.

In a study conducted by Sheerin and colleagues, people with intellectual disabilities identified that independence resulted in more responsibility expected from them.<sup>433</sup> Hollomotz also argues that the experience of 'bad decisions' may increase the autonomy of individuals to assess and manage risk.<sup>434</sup> For Hillman and colleagues, achieving a balance between independence and safety involves promoting and supporting high levels of autonomy through the provision of choice, meaningful community valued activities and reciprocal relationships. This requires a deep knowledge of the person's decision-making ability.<sup>435</sup>

To summarise, as people with disabilities experience greater independence, the risk associated with that independence also increases. Independence of persons with

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<sup>427</sup> (McConkey & Collins, 2010)

<sup>428</sup> (Hillman et al., 2012)

<sup>429</sup> (Hollomotz, 2014)

<sup>430</sup> (Hollomotz, 2014)

<sup>431</sup> (Hollomotz, 2014)

<sup>432</sup> (Hollomotz, 2014)

<sup>433</sup> (Sheerin et al., 2015)

<sup>434</sup> (Hollomotz, 2014)

<sup>435</sup> (Hillman et al., 2012)



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disabilities, however, is often curtailed by organisational policies on risk assessment that tend to over-protect people and by staff's perception of the vulnerability of people with disabilities. A balance between choice, safety and the development of skills to manage independence and risk is recommended.



## 7. What are PCP models of best practice in relation to an exploration of employment?

PCP is widely used for the exploration of employment as part of a comprehensive process involving other activities, such as job development and long-term on the job support. Pectu, Chezan and Van Horn found in a national survey of 62 post-secondary programmes in the USA that PCP is one of the most commonly used employment-related supports for post-secondary education students with intellectual and developmental disabilities.<sup>436</sup> In a study conducted by Migliore, Butterworth, Nord, Cox and Gelb, all employment consultants from 25 employment programmes in the USA reported that they had participated in PCP meetings as part of the activities they performed to support job seekers.<sup>437</sup> Notwithstanding the extended use of PCP for exploration of employment, when the effectiveness of PCP on employment has been examined, research has shown inconsistent results.<sup>438</sup> For example, Robertson and colleagues reported no impact of PCP on employment outcomes<sup>439</sup> while Ratti and colleagues reported mixed results in their literature review.<sup>440</sup> Hendricks highlights the need for longitudinal empirical research, which evaluates intervention approaches throughout the entire support process.<sup>441</sup> In this section, we turn to analyse PCP models and best practice for the exploration of employment.

We first provide a general introduction to two types of employment modalities used with people with disabilities: supported employment and customised employment, as PCP has been identified as a key component of both. We then discuss best PCP practices/models for an exploration of employment and we then outline recommendations.

### 7.1. Supported employment and customised employment

Supported Employment is internationally recognised as the preferred approach for facilitating remunerated work for people with a mild or moderate intellectual disability.<sup>442</sup> Customised Employment is viewed as more suitable for people with severe intellectual disabilities.<sup>443</sup>

In a recent report by the European Commission, Supported Employment was defined as:

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<sup>436</sup> (Pectu et al., 2015)

<sup>437</sup> (Migliore, Butterworth, Nord, Cox, & Gelb, 2012)

<sup>438</sup> (Ratti et al., 2016)

<sup>439</sup> (Claes et al., 2010; Robertson et al., 2006)

<sup>440</sup> (Ratti et al., 2016)

<sup>441</sup> (Hendricks, 2010)

<sup>442</sup> (Beyer, 2012)

<sup>443</sup> (Department of Health, 2009)



“...a scheme that supports people with disabilities or other disadvantaged groups in obtaining and maintaining paid employment in the open labour market. Supportive measures must include assistance to the employee before, during, and after obtaining a job as well as support to the employer. Key to this is the job coach function” (p. 5).<sup>444</sup>

Customised employment is a promising approach to assisting people with significant disabilities to obtain meaningful employment.<sup>445</sup> It is defined under the US Workforce Innovation and Opportunity Act (WIOA) (2014) as:

“competitive integrated employment, of an individual with a significant disability that is based on an individualised determination of the strengths, needs, and interests of the individual with a significant disability, and is designed to meet the specific abilities of the individual with a significant disability and the business needs of the employer” (p. 1634).<sup>446</sup>

### **7.1.1. Supported Employment**

Supported employment emerged in the United States in 1984.<sup>447</sup> Since then, it has increased significantly in numerous countries worldwide promoted by government policies and funding.<sup>448</sup> Supported employment is perceived as having increased benefits over other approaches to occupation for people with an intellectual disability.

The Supported Employment process has evolved from its original basic three step process of ‘place, train and maintain’ managed by a job coach to a much more refined and person-centred model which includes multi-professional facilitation from the business, health, social care and welfare sectors.<sup>449</sup> For example, the European Union of Supported Employment identifies 5 stages:

1. Engagement
2. Vocational profiling
3. Job finding
4. Employer engagement
5. On/Off job support

Ridley and Hunter, based on a study of supported employment in Scotland, suggested, however, that services need to be more user-led, targeting transition goals, and increasing available options, including self-employment.<sup>450</sup> The authors

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<sup>444</sup> (European Commission, 2011)

<sup>445</sup> (Riesen et al., 2015)

<sup>446</sup> (Riesen et al., 2015)

<sup>447</sup> (Mank & Grossi, 2013)

<sup>448</sup> (Cimera, 2012)

<sup>449</sup> (Beyer, 2012)

<sup>450</sup> (Ridley & Hunter, 2006)



suggest that PCP could be an important factor to improve the implementation of supported employment.

### 7.1.2. Customised employment

Customised employment is both a concept and a process.<sup>451</sup> According to Mank and Grossi, customised employment has evolved from initial supported employment strategies. The approach focuses on the skills and interests of the individual in working with employers to make the best use of individuals' skills and interests. Rather than a person employed through a vacancy, a position is customised to an individual's interests and talents and it addresses the employer's needs.<sup>452</sup> Key features that differentiate it from supported employment and other employment strategies include:

- The process is based on the personal strengths of the individual seeking employment (skills, talents and interests) rather than the needs of the local labour market
- The result is a new and unique position customised to the individual through either negotiation with an employer or through self-employment
- It benefits the individual and the employer
- The process may enhance the individual's contribution to the employer by equipping the employee with assets (materials, skills or equipment) to increase the benefit to the employer
- It encourages the use of natural supports available in the employment setting.<sup>453</sup>

Although flexibility is a defining feature of customised employment approaches, there is agreement that the steps generally involved in customised employment are:

- Discovery
- Job search planning
- Job development and negotiation of:
  - a. Customised job
  - b. Provision of supports
  - c. Terms of employment
- Post-employment support.<sup>454</sup>

From a literature review conducted by Riesen, Morgan and Griffin on customised employment covering the period 2006-2015, the authors concluded that while the descriptive studies provide general information about customised employment strategies, they do not establish the evidence base of customised employment with experimental controls.<sup>455</sup> They recommend that interventions have to be described

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<sup>451</sup> (Mank & Grossi, 2013)

<sup>452</sup> (Mank & Grossi, 2013)

<sup>453</sup> (Harvey et al., 2013)

<sup>454</sup> (Harvey et al., 2013)

<sup>455</sup> (Riesen et al., 2015)



using fidelity measures, or indicators of how the intervention was implemented compared to the original design.

## **7.2. PCP best practice/ models for an exploration of employment**

The literature review has identified the following components for an exploration of employment within an individualised approach: getting to know the person and development of a job seeker profile, planning, involvement of the community, state level strategies, training, and other supported employment activities.

### **7.2.1. Getting to know the person and job seeker profile development**

The first step in the exploration of employment through a person-centred approach requires getting to know the person. Examples follow illustrating how knowledge about the person can be achieved through supported employment and through the Discovery method, used with people with significant disabilities in customised employment settings.

#### **7.2.1.1. Supported employment**

In the context of supported employment, a number of models include as a first step gaining knowledge about the person and developing a job profile.

Wehman, Brooke, Brooke, Ham, Schall, McDonough et al. describe an intervention to support people with autism spectrum disorder to gain employment where the first component of the intervention is the development of the job seeker profile.<sup>456</sup> The purpose of this step is to get to know the person. This involves interviews, observations, and informational gathering activities aimed at capturing who the individual is and what his or her interests, desires and skills are. This phase does not aim to deselect people for services but to gather information about the person. This information is used at later stages of the employment process. A central aspect of this process is a situational assessment, which provides an opportunity to perform work tasks in real work environments. The situational assessment is conducted for a 4-hour period in two to three different types of business settings representative of the local labour market and time is spent exploring the community.

Lynas reports on an action research study carried out on Project ABLE (Autism: Building Links to Employment), a Northern Ireland employment service using a supported employment approach for people aged over 16 with autism spectrum disorder.<sup>457</sup> The service's aim is to develop young people's employability skills. In four years, of the 72 young people and adults participating in the programme, 56% achieved employment. The process uses a customised employability programme. The first steps involve:

- An individual induction
- An assessment of established skills, aptitudes, and cognitive abilities

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<sup>456</sup> (Wehman et al., 2016)

<sup>457</sup> (Lynas, 2014)





- A vocational profile highlighting areas of particular interest.

The Working on Purpose model, articulated by Blessing, is a method to engage people with disabilities in an intentional person-centred process of exploration and discovery of potential and purpose, and secondly, to activate this potential in positive and productive ways in employment settings with ordinary or customised jobs, in civic settings where people gather formally and informally and in social networks.<sup>458</sup> The first steps of the method also involve developing knowledge about the person and their employment goals:

- Develop a positive profile of the person
- Define the purpose for seeking employment.

Another example of exploration of employment is provided by Kaehne and Beyer in their evaluation of a pilot programme called the Youth Supported Employment Programme (YSEP) where young people with intellectual disabilities in the UK are encouraged to take on evening and weekend jobs and are supported in this by a non-disabled peer.<sup>459</sup> The first activity of the programme is a home visit to complete an employment profile followed by a search for peers and matching with young people and introductions.

#### 7.2.1.2. Customised employment

In the facilitated version of the Discovery method—the method can also be self-guided—the first question to answer is *Who is this person?* (See table 7.1).<sup>460</sup> The information gathered needs to be translated into possibilities relevant to employment by attending at interests, potential contributions, etc. For example, a person with a significant disability that is able to independently take a CD from its case and play it could be taught to copy CDs for the Human Resources department of a large company. The knowledge about who the person is emerges from a respectful relationship through a variety of activities such as conversation and spending time doing things together as well as more structured interviews and observation. This exploration should occur where the person feels most safe and comfortable, for example in their family home. Discovery moves the facilitator across service systems boundaries and into the person's world to identify unique capacities. The next question to ask in the Discovery process is *Do I want to work?* If the person responds to the question positively, the next stage is to begin a job search and develop a profile.

The Discovery process is also used in the Individualised Career Planning Model, with students aged 14-21.<sup>461</sup> The model commences with the presumption that students are able to work in the community. The goal of the job developer is to identify an

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<sup>458</sup> (Blessing, 2014)

<sup>459</sup> (Kaehne & Beyer, 2013)

<sup>460</sup> (O'Brien & Callahan, 2010)

<sup>461</sup> (Condon & Callahan, 2008)



employment environment suitable to the individual, negotiate the right level of supports and job tasks and ensure a successful employment experience.<sup>462</sup>

**Table 7.1. Discovery process**

1. Explaining the process to the person, allies and supporters, as appropriate
2. Meeting with the person in places where they are at their best
3. Conversing and interviewing the person in activities of everyday life
4. Observing the person in activities of everyday life
5. Participating with the person in familiar and novel activities
6. Reviewing all materials that describe the person's life, sorting for positive information
7. Compiling all materials into a descriptive profile format

Source: O'Brien and Callahan (2010)

### 7.2.1.3. Assessment of work related preferences

A core component of PCP is to plan with the person and their goals, interests and preferences at the centre of the process. However, an issue that has come up in the literature reviewed is the different perceptions in relation to employment that are held by persons with disabilities and their supervisors and parents. Some studies have reported that employees with disabilities perceive themselves to be more effective workers and to require less support than their employer identifies.<sup>463</sup> In one study, Purcell found that young people with autism did not see how autism would impact on their current or future jobs while parents, on the other hand, saw it impacting negatively, but had not discussed this with their children.<sup>464</sup>

Lack of choice may compromise desirable vocational outcomes.<sup>465</sup> Cobigo, Morin and Lachapelle provide the following recommendations for assessing work task preferences with people with significant disabilities, based on the findings of a literature review:

- To present pairs of representative objects and record what selection the person makes
- To reinforce the selection by allowing the person to work on the selected task and to record the behaviours and time of engagement in each task
- To pair the selected task with another task in each trial as long as the same task is chosen again and all options have been presented
- To choose an evaluator who knows the person well and can interpret non-symbolic communication
- To train the person to understand the various connections between:

<sup>462</sup> (Condon & Callahan, 2008)

<sup>463</sup> (Bennett, Frain, Brady, Rosenberg, & Surinak, 2009; Brady, Duffy, Frain, & Bucholz, 2010)

<sup>464</sup> (Purcell, 2014)

<sup>465</sup> (Devlin, 2008; Wehmeyer et al., 2009)



- An object and a task
- Choosing a task and working on the task
- Showing the person that he/she is allowed to choose before starting the trial.

Cobigo and colleagues warn researchers that the lack of a quick means of assessing work task preferences for people with significant disabilities can lead to professionals relying on parents' or caregivers' assessment which is not always a reliable method.<sup>466</sup> One tool that may surmount the problem of assessing preferences in a timely manner is YES (Your Employment Selections), a web based tool to match people with developmental disabilities' preferences with jobs. Yes has 106 knowledge, skill, and ability dimensions requiring an answer. The pilot on 18 young individuals suggests that the instrument may be of use in job matching but further research is required.<sup>467</sup>

### 7.2.2. Planning

Once the information about the person has been gathered and the person has made a decision to pursue employment, planning is the next step. In this section, we describe various examples of planning for employment.

#### 7.2.2.1. Self-Determined Career Development Model

The Self-Determined Career Development Model is a model to develop problem solving skills and to help set and attain career related goals.<sup>468</sup> It is a modified version of the Self-Determined Learning Model of Instruction developed originally to enable teachers to support adolescents to self-direct their learning.<sup>469</sup> The Self-Determined Career Development model focuses on career and employment. The phases of the model address three areas:

1. What are my career and job goals?
2. What is my plan?
3. What have I achieved?

As people with disabilities answer the questions, they must identify a problem, solutions to the problem, barriers to solving the problem and consequences of each solution. Participants are supported to go through the three phases by a facilitator and establish:

- In the first phase, a career-related goal
- In the second phase, a self-monitoring plan
- In phase three, a self-evaluation of their progress toward their goal and modify the action and/ or goal if necessary.

The model has been evaluated with adults with various disabilities and adolescents with emotional and behavioural problems with satisfactory results: helping participants to set and attain job- and career-related goals. In addition, participants

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<sup>466</sup> (Cobigo et al., 2007)

<sup>467</sup> (Morgan, 2008)

<sup>468</sup> (Devlin, 2008; Wehmeyer et al., 2009)

<sup>469</sup> (Wehmeyer et al., 2009)



have expressed high satisfaction with the process.<sup>470</sup> The model has been used to support people before employment and within employment.

7.2.2.1.1. The Self-Determined Career Development model before employment “The Girls at Work” online curriculum combines strategies related to promoting self-determination, implementing the Self-Determined Career Development model, and designing customised employment in the United States.<sup>471</sup> It has proven to be an accessible and motivating option for young women with disabilities by providing a means for mapping out alternative post-school options.<sup>472</sup> The process involves 8 steps (see Table 7.2).

**Table 7.2. The Girls at Work process**

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1. What are my interests and passions that might lead me to a job or career that I enjoy?
  2. What do I know about the job or career that I am interested in now?
  3. What are some job opportunities that I can explore?
  4. What is my road map to explore potential jobs?
  5. What is my employment niche or college goal?
  6. What customised employment options will get me where I want to be?
  7. What supports are available to overcome potential barriers to achieving my goal?
  8. What is my action plan to achieve my goal?
- 

Source (Wehmeyer et al., 2009)

During steps 1 and 2 women identify their job interests. In steps 3 and 4, they explore employment options that match their interests. In steps 5 and 6 they prepare and lead employment team meetings aimed at brainstorming creative employment options, developing business plans, narrowing down one or more job niches. In steps 7 and 8, they bring together resources and information to develop an action plan for employment. The initial evaluation data indicated that 83% of the women involved in the project who had finished high school, were either in employment or attending post-secondary education.<sup>473</sup>

7.2.2.1.2. The Self-Determined Career Development model within employment A study conducted by Devlin examined the impact of the Self-Determined Career Development model on the job performance of four individuals employed in competitive employment in custodial positions in a university campus in the USA.<sup>474</sup> Devlin’s study used a multiple baseline design and a small sample. The study reported that the model is an effective method to teach problem solving skills. The four employees identified work goals and strategies to accomplish them. The following goals were tracked in this study:

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<sup>470</sup> (Wehmeyer et al., 2009)

<sup>471</sup> (Wehmeyer et al., 2009)

<sup>472</sup> (Wehmeyer et al., 2009)

<sup>473</sup> (Wehmeyer et al., 2009)

<sup>474</sup> (Devlin, 2008)



- To learn work-related words
- To identify when cleaning tasks were completed correctly
- To identify task completion and duration of time needed to complete tasks
- To take the local bus transit to and from work.

The study participants' job performance was measured at baseline, following a training phase where participants were supported to work on their goals, and in a maintenance phase. Each of the goals exceeded the expectations set. Job coaches involved with the four employees confirmed the benefits of teaching self-monitoring strategies to increase employees' independence and responsibility.

#### 7.2.2.2. Planning for summer jobs

Carter and colleagues designed an intervention to support people with intellectual disabilities to obtain summer jobs.<sup>475</sup> One of the core components in the intervention is the summer-focused planning with the aim to link summer work experience to longer-term goals.<sup>476</sup> Planning occurred through meetings held between the individual and the community connector (see section 7.2.4.1). Some parents and employers also attended. Community connectors used a written, two-page planning tool template to structure their conversation. The tool included a number of open-ended questions to help link students' summer experiences to their goals for life after high school and to identify potential supports. These questions assisted connectors in identifying:

- Students' short term (spring semester and upcoming summer) and long-term, goals (after high school)
- Places in the community to accomplish their goals
- People, other support and resources needed to implement the plan
- Responsibility for the various aspects of the plan.

Carter and colleagues found that those who participated in the programme (n=67) were 3.5 times more likely to be working over the summer and to work more hours per week. Working did not hinder involvement in other summer activities, such as doing chores, watching TV and engaging in activities related to their hobbies. Nearly all reported that they found the planning component helpful, as it involved actively connecting students to work opportunities.

#### 7.2.2.3. Other examples of planning

In the Individualised Career Planning Model, once the vocational profile is complete a customised employment planning meeting is held to develop a 'road-map'. Students and their families decide who should be in attendance and this usually includes school personnel, employers and the person developing the job. The outcomes from the plan form the content of the representational portfolio, which the job developer uses to approach prospective employers.<sup>477</sup>

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<sup>475</sup> (Carter et al., 2009)

<sup>476</sup> (Carter et al., 2009)

<sup>477</sup> (Condon & Callahan, 2008)



In Project Able, an action plan is developed with achievable goals in the areas of vocational training, work experience and job searching within a period that is judged realistic for the individual. The plan is reviewed at six-month intervals to update and amend if necessary.<sup>478</sup>

The Working on Purpose model proposes to explore the field of opportunity based on the information learned during steps 1 and 2, identify and select the best approach to supporting employment, identify personal and professional networks and develop a plan and take action.<sup>479</sup>

Post-secondary education programmes use PCP to help students identify career goals, work-based learning plans, access to job coaches and developers, job shadowing, paid and nonpaid time-limited internships, work study, and on/off campus integrated competitive employment.<sup>480</sup> Programmes that value self-determination empower students to be involved in and take control over establishing their personal goals, discussing them and reviewing them and advocating for necessary accommodations and technological supports.<sup>481</sup> In the Beyond High School process, it is the student who directs the job identification, development and placement process through the action planning procedure. That is, the student is actively involved in the types of activities traditionally performed by job developers (with their support, of course) and may, in fact, perform some of those activities (e.g., making an initial contact with a potential employment site).<sup>482</sup>

### **7.2.3. Involvement of the community**

Previous research has highlighted the role of the community as key in helping people gain employment. Most traditionally, the community has been the focus of analysis for potential employment opportunities.<sup>483</sup> In a study reported by Carter and colleagues, however, the community was mobilised to develop employment opportunities.<sup>484</sup> The first two components in Carter and colleagues' intervention to improve summer school outcomes involved the following activities: community conversations and resource mapping.

Community conversations were events hosted in communities to foster dialogue around ways that schools, businesses, agencies and organisations, families, youth and others could work to expand employment opportunities for youth with disabilities in the local community through simultaneous small group conversations and a whole

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<sup>478</sup> (Lynas, 2014)

<sup>479</sup> (Blessing, 2014)

<sup>480</sup> (Grigal, Hart, & Weir, 2013)

<sup>481</sup> (Grigal et al., 2013)

<sup>482</sup> (Wehmeyer et al., 2006)

<sup>483</sup> (Lynas, 2014; Vera, 2014)

<sup>484</sup> (Carter et al., 2009)



group discussion to share the points discussed. The groups answered two questions (p. 3):

- “What can we as a community do to increase summer employment opportunities for youth with disabilities?
- What would I be willing to do to facilitate summer employment opportunities for youth with disabilities?”<sup>485</sup>

Resource mapping consisted of identifying and compiling informal and formal resources about disability specific and generally available programmes and supports for youth with disabilities in each local community as well as the state and national levels. Topics included employment, transportation, recreation/leisure, and volunteering.<sup>486</sup>

#### **7.2.4. Roles and training**

This section of the literature review focuses on roles and training specific to employment programmes. Section 5.2.3 of this literature review has explored the role of the PCP facilitator in other settings such as school or day services. The following roles in facilitating the exploration of employment through PCP have been identified: employment specialist or job coaches and the employment liaison.

##### **7.2.4.1. Employment specialists or job coaches**

Employment consultants or specialists (e.g., job developers, job coaches) are key in supporting people gain and maintain employment and supporting employers.<sup>487</sup> In a recent report by the European Commission, it was identified that people with disabilities may transition into employment in the open labour market directly or may go through a number of transitions and the role of the job coach guiding them through these transitions is crucial.<sup>488</sup>

The main tasks of employment specialists or job coaches in relation to exploring employment involve:

- Identifying the capacities of the person and matching them with employment opportunities<sup>489</sup>
- Developing relationships with job seekers, families and community members<sup>490</sup>
- Facilitating the planning<sup>491</sup>

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<sup>485</sup> (Carter et al., 2009)

<sup>486</sup> (Carter et al., 2009)

<sup>487</sup> (Mank & Grossi, 2013)

<sup>488</sup> (European Commission, 2011)

<sup>489</sup> (European Commission, 2011; O'Brien & Callahan, 2010)

<sup>490</sup> (Carter, Trainor, Ditchman, & Swedeen, 2009; European Commission, 2011; O'Brien & Callahan, 2010)

<sup>491</sup> (Carter et al., 2009)



- Negotiating with employers the terms for employment of this person and the adaptations required for successful employment.<sup>492</sup>

In the facilitated version of the Discovery method, the facilitator requires substantial time to identify the capacities of the person and to be able to match them to potential work opportunities.<sup>493</sup> The facilitator models openness, and encourages the recruitment of others in the exploration to organise the support in the pathway to employment.<sup>494</sup>

In Carter and colleagues' intervention, community connectors adopted the role of facilitators.<sup>495</sup> They were special educators or programme support teachers and one person at each school took this role. Their role was to facilitate the planning process, attend their local community conversation, collaborate with the employer liaison, serve as a link to communicate with parents, school staff, employers etc., follow up with the youth, families and others and provide follow up support when needed. For example, when it was determined during the planning process that students would require on-the-job support during the summer, the connectors arranged school-funded job coaching, or directly supported the students themselves.<sup>496</sup>

According to Timmons, Bose and Hall, job developers are the primary person finding jobs and influencing people to take particular jobs, and therefore, their professional quality is key to achieving employment outcomes.<sup>497</sup> Being well informed about support services and networking effectively with those services is reported to be critical to effective transition from school to employment for people with autism.<sup>498</sup> In the USA there are several community service programmes available for adults with intellectual disabilities. Eligibility and availability of services varies based on location so it is necessary to be well informed about resources at a local and national level. In another study conducted in Australia, Kendall and colleagues recommend that rehabilitation counsellors receive training in business plan development to better assist clients who choose self-employment.<sup>499</sup>

Harvey, Szoc, Dela Rosa, Pohl and Jenkins identified 31 tasks relevant to customised employment grouped into 4 main elements (discovery, job search planning, job development and negotiation, and post-employment support). They also identified

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<sup>492</sup> (European Commission, 2011; O'Brien & Callahan, 2010)

<sup>493</sup> (O'Brien & Callahan, 2010)

<sup>494</sup> (O'Brien & Callahan, 2010)

<sup>495</sup> (Carter et al., 2009)

<sup>496</sup> (Carter et al., 2009)

<sup>497</sup> (Timmons, Bose, & Hall, 2013)

<sup>498</sup> (McDonough & Revell, 2010)

<sup>499</sup> (Kendall, Buys, Charker, & MacMillan, 2006)





the following competencies for employment specialists to facilitate customised employment, ranked in order of importance:

- Positive and open approach to life
- Customised job development
- Respecting and relating to others
- Business and employment practices
- Business networking
- Collecting, interpreting and using information
- Communicating with others
- Planning and organising.<sup>500</sup>

In the USA, employment training curriculums are now available and in 2012 the Employment Support Professional Certification Council was established to oversee the first national certification programme for employment support professionals.<sup>501</sup>

#### 7.2.4.2. Employer liaisons

In Carter and colleagues' intervention, another role reported is that of employer liaisons who were, for example, employers or chamber of commerce directors. As part of their role, they attended their community conversation, facilitated community linkages drawing from their networks, collaborated with the community connector and attended the planning process when appropriate.<sup>502</sup>

These roles and training may well address some of the challenges identified for people with intellectual disabilities to attain employment: stigma, uncertainties about applicant abilities, and the complexity of the public disability employment service system.<sup>503</sup>

#### 7.2.5. State level strategies

The model presented by Cohen Hall et al. provides a wider perspective on employment including policy strategies. It is based on the authors' exploration of three States in the USA with high levels of integrated employment.<sup>504</sup> The model is based on case study research including reviews of policy and planning documents and interviews with key stakeholders (administrators in agencies that serve people with intellectual disabilities, community rehabilitation providers and/or disability advocates). In the model, there are key contextual factors that act as catalysts for action:

- Values, for example community inclusion, that guide how service delivery models develop. State-wide training on values occurred in the three high

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<sup>500</sup> (Harvey et al., 2013)

<sup>501</sup> (Mank & Grossi, 2013)

<sup>502</sup> (Carter et al., 2009)

<sup>503</sup> (Henry, Petkauskos, Stanislawzyk, & Vogt, 2014)

<sup>504</sup> (Cohen Hall, Butterworth, Winsor, Gilmore, & Metzler, 2007)



performing states. There was a commitment to training and technical assistance activities, sharing innovative practice, supporting a shared values base and ensuring consistency in addressing the shared goal around integrated employment<sup>505</sup>

- Key players who formed a network of stakeholders committed to the system and worked together. These are described as change agents. Flexible and individualised supports are provided by service providers who can manage employment supports to suit individual needs. This is in contrast to services that are dictated at a state-wide level<sup>506</sup>
- Goal clarity for integrated employment at a systemic level. Integrated employment as a goal emerged from the value base. Clear goals are more likely to be achieved and it means that all stakeholders are working together to achieve a clear outcome.<sup>507</sup>

These factors feed systemic strategies such as flexible funding and flexible policies and the diffusion of innovative practices through training, which, in turn, leads to integrated employment.

#### **7.2.6. Other supported employment activities**

In the studies reviewed as part of this literature review, the following strategies have been found to be complementary to the PCP process for the exploration of employment: job development and career search, long-term support, placement, training and positive behavioural interventions.

Wehman et al.'s study provides an example of the time allocated by employment specialists to support people with autism in the different employment phases. In Wehman et al.'s study, the intervention of the employment specialist was 8.55 hours on average for the jobseeker profile development, 28.43 hours on average for the career search phase, 107.09 hours for the job site training and support, and 27.18 hours for long term supports. The number of hours of support established and then decreased over time, from 18.46 hours the first week to 3.29 hours after 15 weeks.<sup>508</sup> The study found that 82% of 33 participants gained competitive employment in entry-level occupation positions with similar pay to their co-workers without disabilities and working an average of 22.53 hours per week.

##### **7.2.6.1. Job development**

Job development involves a range of activities to secure employment.<sup>509</sup> For example, in Wehman's et al. study, the purpose of job development was for the employment specialist to work with each individual to identify employment options based on the profile. This required an intensive level of intervention on the part of the

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<sup>505</sup> (Cohen Hall et al., 2007)

<sup>506</sup> (Cohen Hall et al., 2007)

<sup>507</sup> (Cohen Hall et al., 2007)

<sup>508</sup> (Wehman et al., 2016)

<sup>509</sup> (EUSE, 2016)



employment specialist. This phase also involved preparing people for their interviews through scripts and role-playing scenarios.<sup>510</sup>

#### **7.2.6.2. On the job support and long term support**

On the job support is provided by the job coach to support the person to perform his or her job adequately but it should eventually be replaced by natural support.<sup>511</sup> Supported employment aims to support people through their careers, in the long term, rather than on one job only.<sup>512</sup> Following with Wehman et al.'s study, once the person obtained employment, two additional steps were implemented: job site training and support (employment specialist helped the individual in learning and adjusting to a new culture, and in the use of applications for support and self-monitoring) and long-term supports to aid job retention (employment specific and individual or community supports).<sup>513</sup>

#### **7.2.6.3. Placements**

Internships or co-ops are supports often used to attain employment.<sup>514</sup> Pack and Szirony used national rehabilitation data in the USA to investigate what factors predict the attainment of competitive employment among people with physical and sensory disabilities.<sup>515</sup> The results support the importance of job placement services to improve the potential for competitive employment. People who had job placement services were nearly four times more likely to be in competitive employment. According to Siperstein, Heyman and Stokes, people with an intellectual disability should be afforded community work experiences earlier in their lives.<sup>516</sup> These experiences should assist them in developing appropriate adaptive behavioural and emotional skills.

#### **7.2.6.4. Training**

Social and communication skills training has been identified as relevant to prepare youth with disabilities to gain employment. For example, Project Able requires their participants to attend vocational and employability training courses and to take part in social and communication skill workshops and associated activities.<sup>517</sup> Pecteu and colleagues also recommended instruction on transition skills to paid employment and training on developing self-advocacy skills.<sup>518</sup>

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<sup>510</sup> (Wehman et al., 2016)

<sup>511</sup> (EUSE, 2016)

<sup>512</sup> (EUSE, 2016)

<sup>513</sup> (Wehman et al., 2016)

<sup>514</sup> (Pecteu, Chezan, & Van Horn, 2015)

<sup>515</sup> (Pack & Szirony, 2009)

<sup>516</sup> (Siperstein, Heyman, & Stokes, 2014)

<sup>517</sup> (Lynas, 2014)

<sup>518</sup> (Pecteu et al., 2015)



#### 7.2.6.5. Positive behavioural interventions

Ham and colleagues present successful case studies of two young Americans with autism spectrum disorder in employment and the support each required for a successful outcome. The authors highlight the importance of positive behavioural intervention plans for some employees with autism spectrum disorder, which included supervision and co-worker training. Both employees with autism spectrum disorder remained in employment for over two years, achieving independence in their work duties with supports fading out over time.<sup>519</sup>

### 7.3. Recommendations

Only empirical studies that examined the effectiveness PCP along with other strategies have been found in this literature review. Therefore, it has not been possible to independently assess the impact of PCP in employment outcomes. The authors concur with other researchers in that there is a need for further longitudinal research with control groups to establish its effectiveness.<sup>520</sup> Based on the findings of this literature review, the authors make the following recommendations:

- Start the process for an exploration of employment by getting to know the person
- Assess personal preferences for employment directly with the person looking for employment rather than with professionals or family members, to capitalise on individuals' choices
- Link short term goals (for example, summer jobs) with longer term goals
- Train people with disabilities in problem-solving skills, self-monitoring and self-evaluation skills with the support of a facilitator to set and attain employment related goals
- Connect individual approaches with system level strategies that work towards the same employment goals
  - Provision of individualised and flexible support
  - Clarity of employment goals so all stakeholders work towards the same goal
  - Commitment to training and technical assistance
- Involve stakeholders in the planning:
  - Those facilitating links in the community
  - Those providing support and monitoring outcomes
- Develop PCP along other complementary strategies including job development, and long-term supports on the job (including work related and community related).

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<sup>519</sup> (Ham, McDonough, Molinelli, Schall, & Wehman, 2014)

<sup>520</sup> (Henry et al., 2014)



## 8. What are the key challenges to the effective implementation of PCP?

The following key challenges have been identified in the literature reviewed from 2005.

### 8.1. Transforming services culture

Changing the culture of organisations has been identified as one of the biggest inhibiting factors to the development of PCP.<sup>521</sup> This is even harder in larger traditional settings where flexible support for PCP is difficult with "all in one" service packages.<sup>522</sup> Services culture determines the relationships between users and providers and, according to Dowling et al., it is reflected in the relationship gap between managers and persons receiving services.<sup>523</sup> Changing services' culture is aggravated by the slow pace of change and practice levels.<sup>524</sup> Part of the challenge is that PCP has become dependent on PCP champions and enthusiastic individuals rather than on service organisations.<sup>525</sup> This echoes Garcia Iriarte and colleagues' findings who reported that managers were perceived by support staff to play a limiting role when it came to the allocation of resources for community inclusion, despite managers being supportive of the idea of community inclusion.<sup>526</sup> Related to the transformation of services culture is the risk that PCP becomes the same for everyone, and not person-centred.<sup>527</sup>

#### 8.1.1. Standardisation of PCP

Organisations have approached the implementation of PCP through standardised strategies that limit the possibilities for individualisation of processes and therefore challenge the core principles of PCP.<sup>528</sup> Cambridge suggested that there is a case for separating PCP from care management since care management has become a highly bureaucratic model, in which large caseloads make it impossible for care managers to develop person-centred approaches.<sup>529</sup> When PCP is solely undertaken by service providers, there is a risk that it becomes an administrative exercise.<sup>530</sup> Among common challenges identified by Parsons and colleagues in their study are that when PCP is done in response to a legislative requirement, it becomes a "system-serving"

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<sup>521</sup> (Cambridge & Carnaby, 2005; Dowling et al., 2007)

<sup>522</sup> (Claes et al., 2010; Dowling et al., 2007)

<sup>523</sup> (Dowling et al., 2007)

<sup>524</sup> (Dowling et al., 2007)

<sup>525</sup> (Cambridge & Carnaby, 2005)

<sup>526</sup> (García Iriarte et al., 2016)

<sup>527</sup> (Cambridge & Carnaby, 2005)

<sup>528</sup> (Parsons et al., 2009)

<sup>529</sup> (Cambridge, 2008; Taylor & Taylor, 2013; Walker, 2012)

<sup>530</sup> (Xie et al., 2008)



exercise. Similarly, Claes and colleagues state that PCP can become a paper exercise with no connection to the real lives of individuals.<sup>531</sup>

Dowling and colleagues, using Mansell and Beadle-Brown research, state that unless PCP has legal backing, it will be very difficult for service users to make a complaint against service providers for the provision of personalised services.<sup>532</sup>

## **8.2. Services accountability to persons with disabilities and to funders**

Robertson and Emerson conclude from their review that there is an indirect and tenuous relationship between planning and outcomes.<sup>533</sup>

Good planning meetings that produce good plans is only a starting point in the planning process: there must also be implementation of plans and realisation of goals that improve people's lives. (p. 290)

Claes and colleagues also caution that too much optimism may lead to unrealistic goals, unsuccessful outcomes and unrealised expectations.<sup>534</sup> The challenge for services is that they are accountable to both funders and persons with disabilities. However, these accountabilities are often disconnected.

In a study conducted by García Iriarte on participation of people with intellectual disabilities in their individual service plan meetings, the findings suggest that the organisation providing services to people with intellectual disabilities was accountable to funders and regulatory bodies for developing and keeping planning records of individuals, not for fulfilling the goals of people with intellectual disabilities.<sup>535</sup> This finding also supports Linehan and colleagues' research who identified that staff working in intellectual disability services perceived planning as "a bit of waste", more relevant to organisational compliance than to individuals' outcomes.<sup>536</sup> The following quote by a manager of an organisation in McConkey et al.'s study illustrates how organisational procedures and accountabilities may limit people from setting their personal goals:

We have a role in facilitating, we have a role in enabling, but sometimes our role is to just get out of the way (of people's lives) and not be exercising incorrect and undue influence over decisions or resources or whatever it might

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<sup>531</sup> (Claes et al., 2010)

<sup>532</sup> (Dowling et al., 2007)

<sup>533</sup> (Robertson & Emerson, 2007)

<sup>534</sup> (Claes et al., 2010)

<sup>535</sup> (García Iriarte, In press)

<sup>536</sup> (Linehan, 2015)



be; which is very difficult because you have all the accountabilities still (p. 100)

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A second and related problem is that social service organisations have traditionally tracked outputs (evidence of conducting activities) instead of outcomes (expected results from the activities conducted).<sup>538</sup> This finding concurs with Fitzsimons's, as he found that PCP may increase community presence (output) but may not facilitate community participation (outcome).<sup>539</sup>

The challenge is for services to measure outcomes identified by people with disabilities and to become accountable to people for the achievement of their personal outcomes. For regulatory bodies, the challenge is to harmonise their quality requirements for service providers with personal outcomes.

### **8.3. Limited choice for people with intellectual disabilities**

The choices for people with intellectual disabilities are limited by various factors: lack of person centredness and a top down approach, conservative risk assessment, community barriers, and systematic barriers.

A top down approach strongly limits the possibilities for flexible, individualised support arrangements. When PCP is professional-dominated, the choices of people with intellectual disabilities may be limited. This is the case if others judge their wishes as unrealistic, or involving high risk for the person, when there is a conflict of views between the person and the family/representative, or if the person has communication difficulties.<sup>540</sup> Persons with intellectual disabilities' limited life experience can also narrow the range of goals set in a plan. In this context, Parsons and colleagues recommend using the experiences of other people to help the person articulate their own goals and wishes for the future.<sup>541</sup> A communication ally with integrity and guided by a person-centred vision is recommended to support and advocate for people with communication difficulties.<sup>542</sup>

Robertson and colleagues identified systematic barriers that can prevent the accomplishment of goals. These include: unavailability of services (day services, housing, waiting lists and employment opportunities), lack of involvement of the local community (difficulty developing circles of support), transport, staff time, participants' behaviour, goals that do not reflect participants' wishes and unrealistic goals.<sup>543</sup> Positive action to complement PCP and to remove barriers to employment,

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<sup>537</sup> (McConkey et al., 2013)

<sup>538</sup> (García Iriarte, Suárez-Balcázar, & Taylor-Ritzler, 2011)

<sup>539</sup> (Fitzsimons, 2012)

<sup>540</sup> (Parsons et al., 2009)

<sup>541</sup> (Parsons et al., 2009)

<sup>542</sup> (Parsons et al., 2009)

<sup>543</sup> (Robertson et al., 2007)



mainstream housing options and specialist services is recommended, in order to play a stronger role in enabling more inclusive social networks.<sup>544</sup>

Cumella also warns that people with intellectual disabilities may be seen as a docile group for whom professionals make decisions through assessments such as PCP. This may influence public perceptions of people with disabilities as the responsibility of charitable organisations rather than of public funding.<sup>545</sup>

#### **8.4. Coordination of inter-agency and natural support**

Support outside a primary service provider organisation is difficult to coordinate. Dowling and colleagues identified that inter-agency collaboration is a challenge to PCP.<sup>546</sup> Furthermore, Small, Raghavan and Pawson's findings showed that there is a reliance on family and school networks.<sup>547</sup> When people leave education there is a significant gap in their social network. The authors suggest that a more appropriate approach to transition planning than PCP would be to work with the person and their family to develop connections and supports that extend beyond the education setting. This recommendation aligns with Robertson and colleagues' finding that barriers to PCP were experienced in the involvement of people other than paid staff in the process.<sup>548</sup>

Circles of support are difficult to establish.<sup>549</sup> The language of PCP implies a community base that is atypical in an increasingly individualistic society.<sup>550</sup> For example, a study conducted in Ireland found that older people with intellectual disability present a very different profile to that of the general ageing population being mostly single, unmarried and without any children or grandchildren.<sup>551</sup> They are more reliant on siblings and their extended family to develop social networks. However, this is further complicated by family members living in different neighborhoods than people with intellectual disabilities.<sup>552</sup>

Bigby and Knox found in a study conducted with older people with intellectual disabilities that they lived in two separate worlds, family and services, with little or absent communication between the two.<sup>553</sup> Communication was about everyday matters, no one had a complete picture of the person, in the family or in the service, and no one had the responsibility to know more about the person.

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<sup>544</sup> (Robertson and Emmerson, 2007)

<sup>545</sup> (Cumella, 2008)

<sup>546</sup> (Dowling et al., 2007)

<sup>547</sup> (Small, Raghavan, & Pawson, 2013)

<sup>548</sup> (Robertson et al., 2007)

<sup>549</sup> (Claes et al., 2010)

<sup>550</sup> (Dowling et al., 2007)

<sup>551</sup> (McCausland et al., 2014)

<sup>552</sup> (McCausland et al., 2014)

<sup>553</sup> (Bigby & Knox, 2009)





No one knew these older people well enough or had a sufficient sense of responsibility towards them to plan with them, as a whole person, collaboratively across both the boundaries of family and service worlds (p. 226).

### **8.5. Over-reliance on tools**

Parsons and colleagues state that there is an over-reliance on standardised planning tools (for example, the completion of a lengthy document by the service provider to have formal requirements met).<sup>554</sup> The focus of PCP should be on the quality processes and outcomes rather than on tools. In the study by Parsons and colleagues, the best case study providing the best outcomes for the individual did not use formal tools or processes, individual needs planning was carried in a regular informal way, without specific directed questions. However, all of the people had a strong commitment to person-centeredness. This case challenges the assumptions that planning requires a tool, a planning meeting or a product (the plan) that should be produced.<sup>555</sup> A recent report published in Ireland by Genio also highlighted that although needs assessment and planning tools can be helpful, they can impose a deficit view on the person that can subsequently lead to inappropriate support.<sup>556</sup>

### **8.6. Practicalities of planning**

For the 28 people who did not receive a plan in the Roberston and colleagues' study, the most common reason identified was facilitators leaving or not being available. Other factors were lack of time and staffing issues.<sup>557</sup> The practicalities of organising meetings in relation to time and scheduling constraints, organising people to attend and venues, and plans created in times of crisis have limited the authenticity of the process.<sup>558</sup> Parsons et al. found in their study that planning was at times crisis driven and therefore carried out under strict time constraints that limited the person-focus and authenticity.<sup>559</sup> Other factors commonly identified as hindering people achieving goals included:

- Delays in planning for activities (for example, information gathering or risk assessments)
- Lack of staff supporters
- Insurance issues
- Transport issues.<sup>560</sup>

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<sup>554</sup> (Parsons et al., 2009)

<sup>555</sup> (Parsons et al., 2009)

<sup>556</sup> (Genio, 2014)

<sup>557</sup> (Robertson et al., 2007)

<sup>558</sup> (Parsons et al., 2009)

<sup>559</sup> (Parsons et al., 2009)

<sup>560</sup> (McConkey & Collins, 2010)



## 8.7. Personal factors

Involving certain groups of people in the planning process has been found to be another challenge, for example, individuals from ethnically, linguistically and culturally diverse backgrounds, and those with communication difficulties.<sup>561</sup> In the study by Robertson et al. it was found that people with mental health problems, autism, mobility difficulties and health problems were less likely to have a PCP, and if they received a plan, they were less likely to benefit from it. However, characteristics of the person such as physical and health related factors were ranked low as barriers to having goals met.<sup>562</sup> McConkey and colleagues found that having an individualised /person-centred or outcomes plan was most commonly reported for those who moved to group homes or were already in personalised settings and less for those living with family carers.<sup>563</sup>

## 8.8. Resources

Inflexible funding structures have been identified as another challenge to the implementation of PCP.<sup>564</sup> Limited funding for projects also curtails the opportunities to create sustainable change.<sup>565</sup> In this context, other jurisdictions have adopted individualised funding as a way to develop new opportunities for person centred-approaches.<sup>566</sup>

To summarise, the following challenges to the implementation of PCP have been found:

1. Transforming service culture
  - Standardisation of PCP
2. Services accountability to persons with disabilities and to funders
3. Limited choice for people with intellectual disabilities
4. Coordination of inter-agency and natural support
5. Over-reliance on tools
6. Practicalities of planning
7. Personal factors
8. Resources

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<sup>561</sup> (Claes et al., 2010)

<sup>562</sup> (Robertson et al., 2007)

<sup>563</sup> (McConkey et al., 2013)

<sup>564</sup> (Dowling et al., 2007)

<sup>565</sup> (Walker, 2012)

<sup>566</sup> (Parsons et al., 2009)



## 9. What are recommendations emerging from the literature on PCP implementation?

Cambridge and Carnaby ponder how realistic is PCP and whether we need to expand the number of person-centred strategies to complement PCP or even to replace it.<sup>567</sup> Given the body of evidence on the effectiveness of PCP, there is consensus among researchers that it is more about philosophy and values than about the planning per se.<sup>568</sup> This section presents a summary of the guidelines to implement PCP identified by the authors of this report based on the preceding sections. Some of the guidelines are based on empirical evidence and some are based on conclusions and recommendations made by researchers and authors drawing from their research and ample knowledge of the field.

### 9.1. Develop a person-centred culture in the organisation

- PCP should be underpinned by person centredness
- Person centredness should permeate all levels of service provider organisations
- PCP should be implemented as part of a broader organisational change and not adopted as a new service
- PCP should not be tied to care management but it should underpin it.

### 9.2. Approach PCP from an advocacy perspective

- PCP should be considered as a form of self-advocacy
- Organisations and facilitators should work on broader systems change to increase the options for people with disabilities to participate in employment, education, community life, etc
- PCP should be implemented along with other strategies that enable the person to accomplish goals such as inter-agency collaboration and connections with wider self-advocacy networks.

### 9.3. Prioritise individual outcomes and services accountability to individuals

- Organisations should collaborate to provide services to individuals that enable them to accomplish their goals
- PCP should be a three stage process involving: preparation and training, facilitation of meetings, and importantly, implementation of plans and follow up
- PCP should be accessible and ownership of the plan and outcomes should lie with the person who is the focus of the PCP
- PCP should include goals on life-style areas and these should not be constrained by the services provided by an organisation

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<sup>567</sup> (Cambridge & Carnaby, 2005)

<sup>568</sup> (Cambridge & Carnaby, 2005; Claes et al., 2010; Dowling et al., 2007; Parsons et al., 2009; Taylor & Taylor, 2013)



- PCP should be monitored and reviewed regularly
- PCP should be implemented in combination with other naturally occurring circumstances to increase the personal networks of people with intellectual disabilities
- PCP should be responsive to personal and cultural characteristics
- PCP should be implemented alongside flexible models of funding
- PCP should aim to achieve a balance between empowering people to develop skills to manage their own risks and taking responsibility for those risks.

#### **9.4. Involve the individual, their family, paid support and natural support**

- PCP should involve the person, paid support and informal support
- The involvement of people with intellectual disabilities in the plan should be made clear:
  - People with intellectual disabilities should avail of individualised preparation to participate in their PCP meetings
  - People should have access to an independent advocate to facilitate training and/or provision of information.
- Facilitators, that ideally are independent from the main service provider organisation, should facilitate the coordination of plans involving different types of support and services including those not provided by the organisation facilitating PCP
  - Facilitators have a relationship with the person before the planning, facilitating is part of their job description, they are supported by the organisation, and they should be experienced in PCP
  - When facilitators have a dual role of facilitating and implementing plans, this leads to conflict in their performance. Therefore, these two roles should be undertaken by different people
- Paid staff who support the implementation of the plan should be involved in planning
- PCP should address a lack of support networks at an early stage.

#### **9.5. Provide training to all involved**

- Training for the person who is the focus of the PCP
  - Training is recommended on PCP and self-directed planning, decision making, choice-making skills, identifying preferences, goal setting, communication skills, self-advocacy and rights, self-determination, social capital, funding options, individualised supports, expectations of PCP, and the availability of services
- Training for facilitators
  - Training is recommended in the following areas: values/principles of PCP, communication (listening, accessible communication, support for people with no verbal communication), group dynamics and facilitation skills, community support, networking and identifying community resources



- Training for staff implementing the plans
  - Staff training is recommended on PCP, communication (stepping back, following the lead of the person, deep listening, planning and developing accessible materials), community inclusion, human rights to facilitate an advocacy function, individualised support, and training on active support
  - Staff and managers should be trained on person centredness and PCP implementation strategies.
- Training for families
  - Training for families should focus on PCP, choice making, individualised supports, expectations for the planning process, self-advocacy, availability of services and legal and financial aspects of planning.

### **9.6. Provide the person and the family with authority over the plans**

- PCP should be conducted in an informal way to empower the person and the family and to avoid being dominated by professionals
- PCP should be governed by policies that legitimate the decisions made by persons with disabilities and that make organisations accountable for goal accomplishment.

### **9.7. Implement PCP for an exploration of employment alongside other strategies**

- Exploration of employment should start by getting to know the person
  - It should provide opportunities to the person to make work-related choices
- It should involve community stakeholders in the planning process
- It should connect individual approaches with system level strategies
- All stakeholders should work towards the same employment goals
  - Short term goals should be linked with long term goals (for example, summer employment with long term goals of employment)
- It should involve training of people with disabilities in problem-solving skills, self-monitoring and self-evaluation



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